2018-05-09

Protective Multi-level Factors in Adolescents of Mothers with Mental Disorders

Chante Washington-Oates

University of Miami, c.washington2@umiami.edu

Follow this and additional works at: https://scholarlyrepository.miami.edu/oa_dissertations

Recommended Citation
https://scholarlyrepository.miami.edu/oa_dissertations/2061
PROTECTIVE MULTI-LEVEL FACTORS IN ADOLESCENTS OF MOTHERS WITH MENTAL DISORDERS

By
Chante Evette Washington-Oates

A DISSERTATION

Submitted to the Faculty of the University of Miami in partial fulfillment of the requirements for the degree of Doctor of Philosophy

Coral Gables, Florida

May 2018
Maternal mental disorders (MD), including substance use, are chronic conditions associated with poor child mental health. Yet, some children of these mothers thrive and experience healthy development and functioning. Despite this, little research examines protective factors, e.g., parenting practices and self-management beliefs and behaviors, in children of mothers with MD. This dissertation was ancillary to a randomized trial of a family-based intervention for mothers with MD and their children. The aims of this dissertation were to: 1) examine whether maternal positive parenting practices are related to adolescent emotional (internalizing) and behavioral (externalizing) problems, after controlling for mother’s psychological distress and substance use, 2) gain an understanding of adolescents’ individual-level resources regarding their abilities to self-manage, and 3) describe the challenges, problem-solving approaches, and lessons learned of conducting community-based, family research among mothers with MD and their children. Theories guiding this study were Ecodevelopmental Theory, and the Individual and Family Self-Management Theory.

Aim 1 was conducted through secondary analysis of baseline data from a randomized trial of a family-based intervention (hereafter referred to as the parent trial) with 90 mothers and 118 adolescents. For Aim 2, qualitative interviews with 19
adolescents of mothers from the parent study were conducted. Aim 3 was conducted through a review of administrative proceedings from the parent trial (e.g. study team meeting/contact notes, IRB modifications, study enrollment and contact logs and reports) and were analyzed to inform challenges and lessons learned in conducting community-based research with families affected by maternal mental disorders.

Findings from the quantitative analysis demonstrated significant relationships between 1) the mother’s substance use and child externalizing problems, 2) the mother’s psychological distress and child internalizing problems, and 3) the mother’s parental involvement and child internalizing and externalizing problems. Three major themes emerged from the qualitative analysis: (1) the construction of healthy, positive self-concepts, (2) resolving demands through engaging in various forms of self-regulation during normal and challenging situations, and (3) balanced socialization – the interplay between individualism and social connections. Challenges identified related to participant recruitment, retention, burden, and service needs; community provider engagement; and protection of vulnerable participants. Three “lessons learned” in addressing such challenges included: 1) building relationships with members of vulnerable populations; 2) community provider engagement when seeing the value to their clients; and 3) organized flexibility.

This study provides information on individual and parental factors that can protect adolescents of mothers with mental disorders and their families and approaches to overcome challenges conducting research with these families. This information is intended to inform clinical practice, policy and future research.
DEDICATION

I dedicate this dissertation first and foremost to God, the Almighty, for my Lord and Savior, Jesus Christ, who is and remains the center of my life, and to my loved ones - including family and friends.

To my husband, Michael Terail Oates, who has offered unwavering support. Your encouraging words pushed me to never give up, your sense of humor balanced out those challenging moments, your delicious meals provided me the nutrients needed to get the job done, you getting me up and out of bed when I was moving too slow, and your care for our children sustained me. Thank you, Mike, for your support and encouragement!

To my late grandparents (including in-law), General and Thelma Washington and William Oates, Sr. You provided the ingredients to this recipe titled, Victory. These ingredients included: unwavering faith in God, family love and love for others, endurance, service to others, and commitment to excellence. Thank you, grandparents, from the depths of my soul!

To my parents, Arthur and Laura James Washington, Sr. who implanted in me the love for God, the strong willpower to succeed, and the passion to help/serve those in need. From early age, you spoke success over me, provided me the best resources needed for me to thrive (including your love and access to high-quality education), and always believed in me. You emphasized the importance of higher learning and perseverance despite adversity. I am who I am because of God first, then you both setting the best examples in the home, in our family, and in the community. Thank you, Da and Ma, for your love and guidance!

To my children, Saniya Chardae Oates (my first-born) and twins Mikah and Makhi Terail Oates, also known as ‘M&M.’ I am forever grateful for your unwavering love, patience and confidence in me. This means more to me, than you’ll ever know. From the day you were born, you have been nothing but blessings to me. You inspire me to achieve greatness! Saniya, because of what you have done for me, I finished! Thank you babies!

To my dissertation chair and mentor, Dr. Victoria B. Mitrani. Thank you for always believing in my abilities to succeed. You generously outpoured resources from the start of my PhD studies and faithfully, guided me. Your availability, constructive feedback, obvious commitment to my success, exemplary leadership, and remarkable contributions to my academic and professional growth all were integral to my success. I look forward to continued collaborations. Thank you Dr. Mitrani for being a blessing in my life!

Lastly, to the participants of Project I.M.P.A.C.T. (Inspiring Minority Youth and Families to Address Challenging Times), other families affected by mental and substance use disorders, and adolescents whose voices remain unheard. I will do what I can as a nurse scientist and educator to continue shining the light on your thriving capacity and resources, and improve your quality of life.
ACKNOWLEDGEMENTS

There are so many people responsible for nurturing my growth as a person, nurse scientist, leader, and professional, I must recognize.

First, I thank God for the vision and provision, his grace and mercy!

Drs. Victoria Mitrani, Brian McCabe, Anthony Roberson and Dean Prado - my dissertation committee members. Your guidance, patience, wisdom, accessibility, solid support, and helpful resources have been key in me completing this degree. I cannot thank you enough for deepening my understandings as well as your efforts and time. Your individual assets inspire me to achieve excellence and serve with compassion. I’m forever grateful of your service on the committee.

I would like to thank Dean Munro and former Dean of the University of Miami School of Nursing and Health Studies, Dean Peragallo, for fostering an academic environment committed to excellence, leadership, scholarship, service, and effective collaborations within the institution and communities served.

Much of my progress was achieved due to the incredible support of faculty and staff of the School of Nursing and Health Studies, the University of Miami’s Graduate School, and former Center of Excellence for Health Disparities (EL CENTRO), colleagues, and volunteers I had the pleasure of guiding and collaborating.

To the Banyan Health Systems personnel and Healthy Home team, collaborating with you all made this journey worthwhile as it demonstrated the power of a team, coordinated approach in working with vulnerable populations.
I appreciate Banyan for providing me access to adolescents and their mothers who participated in the study. Each of you hold a special place in my heart. Your work as well as the work of other community agencies including the Village, Borinquen, and Agape is much needed, and commendable.

To my sister, Cheri Bonita McDowell, the oldest sibling of us all, where do I begin. When I needed you, you never hesitated to be there. You made sure I completed this degree, even if it meant you going the extra mile and giving your last. I don’t think you’ll ever know how much I appreciate all your sacrifices and confidence in me. Hopefully, these words help you realize the important role your support played in this process and my life!

To my brother, Arthur James Washington, Jr. We did it brother! I say ‘we’, because your continuous encouragement and example of leadership and service as you protected and served in the call of duty inspired and motivated me. Thank you for pushing me to never give up and to go as high as I could go in this flight heading northbound.

To my other sister, Chandra Lynette Washington, I thank you for stepping in and doing what means most to me, loving and caring for my children when I was busy working. Most importantly, thank you for never doubting I was going to make it through. You have shown me what strength looks like and for this I thank you.

To my nieces and nephews, Cherika Monique McDowell, Arthur James Washington III, Anthony Jamal Washington, Robert Lewis Lester III, Aaliyah Jade Lester, Khamani Anton Thurman, Ariyelle Kimora Thurman, Dylan Jamon Gibson, and Aria Jade Washington. Thank you for the love, those many joyful
moments that took away from the hardships, your belief in me, and being there when I
needed. I thank God for each of you and will continue to be a good role model for you.

My heartfelt thanks to my godparents, Mr. & Mrs. Perry Lee Anderson, for
being true examples of exemplary character and integrity. Thank you for the countless
moments of support and your sacrifices to be good role models to myself and countless
others in the communities you served.

Thanks to my grandmother-in-law, Mary Oates, and parents-in-law, Mr. &
Mrs. Craig Maxwell, for the prayer sessions. It was empowering knowing you were
praying and cheering for me.

To my University of Miami McKnight Doctoral family, mentors, and the UM
Alumni Association, I appreciate the face to face and telephone conversations, emails
and events that not only offered academic support and opportunities to enrich my
learning experiences, but spiritual messages of inspiration and encouragement greatly
needed and right on-time.

The financial support throughout my Ph.D. studies of the: University of Miami
School of Nursing and Health Studies and its Beta Tau Chapter of the Sigma Theta Tau
International, the McKnight Doctoral Fellowship Program, the Miami Police Veterans
Association, and loved ones were greatly appreciated.

A special thanks to our family pet, “Bubbles,” for barking loud enough when
persons entered our yard when I was deeply immersed in work. Your energy uplifts me!

To my remaining family and friends, including in-laws, and educators,
my heartfelt gratefulness is extended to each of you. You understood when I did not
attend functions and always knew I’d complete this journey. Thank you!
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>LIST OF FIGURES</th>
<th>ix</th>
</tr>
</thead>
<tbody>
<tr>
<td>LIST OF TABLES</td>
<td>x</td>
</tr>
</tbody>
</table>

Chapter

1 INTRODUCTION
- Background .......................................................... 1
- Aims of the Dissertation .................................................. 13
- Theoretical Framework .................................................... 14
- Specific Aims and Abstracts ................................................ 15

2 PARENTAL INVOLVEMENT AS A PROTECTIVE FACTOR AMONG ADOLESCENTS OF MOTHERS WITH MENTAL DISORDERS
- Background .......................................................... 21
- Theoretical Framework .................................................... 24
- Study Aims and Hypotheses .................................................. 25
- Methods .......................................................... 27
- Analyses .......................................................... 33
- Results .......................................................... 34
- Discussion .......................................................... 37
- Implications for Research and Practice ........................................ 39

3 LIVING WITH A MOTHER WITH A MENTAL DISORDER: SELF-MANAGEMENT OF ADOLESCENTS AS A PROTECTIVE FACTOR
- Background .......................................................... 40
- Theoretical Framework .................................................... 43
- Methods .......................................................... 45
- Analysis .......................................................... 49
- Findings .......................................................... 51
- Discussion .......................................................... 74
- Implications for Research and Practice ........................................ 78

4 COMMUNITY-BASED RESEARCH WITH FAMILIES OF MOTHERS WITH A MENTAL DISORDER: LESSONS LEARNED
- Background .......................................................... 82
- Methods .......................................................... 84
- Results .......................................................... 86
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discussion</td>
<td>99</td>
</tr>
<tr>
<td>Conclusion</td>
<td>101</td>
</tr>
<tr>
<td>5 DISCUSSION</td>
<td></td>
</tr>
<tr>
<td>Major Dissertation Findings</td>
<td>103</td>
</tr>
<tr>
<td>Limitations</td>
<td>106</td>
</tr>
<tr>
<td>Future Direction</td>
<td>107</td>
</tr>
<tr>
<td>Implications for Nursing Practice</td>
<td>107</td>
</tr>
<tr>
<td>References</td>
<td>109</td>
</tr>
<tr>
<td>Figures</td>
<td>128</td>
</tr>
<tr>
<td>Tables</td>
<td>133</td>
</tr>
<tr>
<td>Appendix</td>
<td></td>
</tr>
<tr>
<td>A. Adolescent Interview Questions</td>
<td>145</td>
</tr>
</tbody>
</table>
**LIST OF FIGURES**

<table>
<thead>
<tr>
<th>Figure</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Figure 1</td>
<td>The integrated theoretical framework in the context of adolescents of mothers with mental disorders</td>
<td>128</td>
</tr>
<tr>
<td>Figure 2</td>
<td>Hypothesized SEM model in predicting adolescent mental problems</td>
<td>129</td>
</tr>
<tr>
<td>Figure 3</td>
<td>Results of the Hypothesized SEM model in predicting mental problems</td>
<td>130</td>
</tr>
<tr>
<td>Figure 4</td>
<td>Grouping of themes and subthemes</td>
<td>131</td>
</tr>
<tr>
<td>Figure 5</td>
<td>Participant flow through the study</td>
<td>132</td>
</tr>
</tbody>
</table>
LIST OF TABLES

Table 1. Characteristics of Mothers................................................................. 133

Table 2. Characteristics of Children Reported on by the Mothers................................................................. 136

Table 3. The Relationship Between Psychological Distress, Positive Parenting Practices, and Adolescent Mental Wellbeing Among a Sample of Adolescents of Mothers with Mental Disorders......................... 138

Table 4. The Relationship Between Mother’s Psychological Distress and Substance Use and Positive Parenting Practices Among a Sample of Adolescents of Mothers with Mental Disorders......................... 139

Table 5. Gender and Race/Ethnicity Frequency Distribution by Age Group................................................................. 140

Table 6. Themes, Categories, and Subcategories: Definition of Concepts.............. 141
CHAPTER 1: INTRODUCTION

Background

Women are disproportionately affected by mental disorders (World Health Organization, 2016; National Institute of Health [NIH], 2016), which represent a large burden of disability on women worldwide (NIH, 2016; Whiteford et al., 2015) as well as adverse consequences for their families (Conners-Burrow et al., 2013; Hser et al., 2013; VanDeMark et al., 2005). The harmful effects of maternal mental disorders (MMD), which include substance abuse, on children’s health is well documented (Conners-Burrow et al., 2013; Hser et al., 2013; VanDeMark et al., 2005). These children are particularly vulnerable due to disruptions in parenting (Arria et al., 2012; Dvir, 2012; Haggerty et al., 2008; Perera et al., 2014), interruptions in their social support, family discord and separation related to loss of maternal custody, neglect (Atkins, 2010; Kohl et al., 2011), decreased parental monitoring and supervision (Latendresse et al., 2008; Stanger et al., 2004), and problematic parent-child interactions (Johnson, Cohen, Chen, Kasen, & Brook, 2006; Arria et al., 2012; Stanger et al., 2004). Given these reasons, the need to focus on these families as a susceptible group is among the highest national health priorities recognized by the Surgeon General in his 2016 report on health and substance abuse. Despite this urgent need, inaccessibility to family support services for these children and families remain, further highlighting the urgency to focus on protecting and addressing the needs of these families.

Mental disorders (MD) are considered a health crisis impacting 1 in 3 American households (Facing Addiction, 2017). MD are chronic relapsing conditions, associated with poor health outcomes for the individual with the disorder as well as for
children being raised by individuals with these problems. Specifically, maternal mental disorders (MD) are significant public health problems affecting child/adolescent health. Despite treatment efforts, MD remain a public health problem that affects millions of women (Substance Abuse and Mental Health Service Administration [SAMHSA], 2008), many of whom are of childbearing age. Women with MD tend to be the sole caretakers of their children (Dvir, 2012). While maternal MD produce harmful trickle-down health effects on millions of children who live with their mothers (SAMHSA, 2009), some children manage to thrive and experience healthy development despite their mother’s problems (Gelkopf & Jabotaro, 2013; Hser et al., 2014; VanDeMark et al., 2005). The preponderance of literature regarding the effects on children of maternal MD has focused on the deficits and risks in these families, despite recent evidence indicating the significance of illuminating protective factors (CDC, Protective Factors, 2015; Children’s Bureau, 2015).

The overarching purpose of this dissertation is to examine protective factors that mitigate the risks to adolescents of being affected by maternal MD, and that have a positive influence on children’s mental health outcomes. This dissertation focuses specifically on protective factors at the levels of the child and parenting as well as on child outcomes of internalizing and externalizing problems among pre-adolescent and adolescent children (ages 10 to 19) of mothers with MD. The entire age group of 10-19 years is hereafter referred to as adolescents.

Prevalence of Mental Disorders Among Women

According to the National Survey on Drug Use and Health, more than 3 million women of childbearing age experience Mental Health Disorders, or MHD (Substance
Abuse and Mental Health Services Administration, 2012). Additionally, approximately 1 in 2 women of child-bearing age (i.e., aged 18–44 years) uses psychoactive substances, such as illicit drugs or alcohol (Women’s Health, 2014). An estimated 5.7% of females 12 years and older abuse substances (SAMHSA, 2012), and females constitute more than 50% of the 2.4 million Americans using prescribed medications for nonmedical reasons for the first time within the previous year (NIDA, 2011). According to the findings of the Treatment Episode Data Set (TEDS), pregnant females aged 15 to 44 accounted for 63.8% of substance abuse treatment admissions while non-pregnant females aged 15 to 44 accounted for 49.1% of admissions in 2010 (SAMHSA, 2013c).

Mental illness is projected to be the leading cause of disability by 2030 (World Health Organization, 2011). Mental health problems, such as depression, anxiety, post-traumatic stress, and bipolar disorder, represent health disparities that are more prevalent among women, many of whom are of childbearing age (SAMHSA, 2013a; SAMHSA, 2013b). For instance, according to the findings of the National Survey on Drug Use and Health 2012 report, women constituted 29.4 million of the ambulatory care visits with a primary mental health diagnoses between 2005 and 2008, as compared to 18.5 million of visits for men (SAMHSA, 2014). In 2007, women accounted for two-thirds of users of mental health services (Atkins, 2010). Estimations are 8.4% of women experience depression, as compared to 5.2% of men who experience this condition in any given year; women are approximately twice as likely as men to experience depression (Atkins, 2010; SAMHSA, 2013b).

Millions of children live in the same household as a parent with a mental disorder (SAMHSA, 2009). More specifically, more than 8.3 million, about 1 out of 10, children
under the age of 18 lived with at least one parent who abused alcohol or an illicit drug during the past year (SAMHSA, 2009). Approximately one million adolescents in the US live with a substance-using parent (SAMHSA, 2009). Among adolescents, an estimated 12% aged 6 to 11 years and 9.9% of youths aged 12 to 17 years live in a household with a parent with a substance use disorder (SAMHSA, 2009). More specifically, more than 1 million children in the US live with their mother who has a MD (Lipari & Van Horn, 2017; NSDUH, 2015). Additionally, between 50% and 66% of parents with a severe mental disorder live with one or more children below 18 years (Mental Health Foundation, 2017). Further, women with MD are more likely than men to have responsibility for the care of their dependent children (Kauffman et al., 1997; Nelson-Ziupko et al., 1995; Osborne, 2009).

The Intersecting Susceptibilities of Women with MD

Co-occurrence and overlap of symptoms exists across substance use and mental illness. According to the National Survey on Drug Use and Health, approximately 2 million women of child-bearing age experience co-occurring mental disorders (SAMHSA, 2003). Researchers report that among a sample of 396 substance-abusing mothers, 21% experienced depression, 35% experienced anxiety, 40% suffered from cognitive dysfunction, such as difficulty concentrating and understanding, and 22% experienced previous inpatient psychiatric treatment while 50% underwent outpatient psychiatric treatment at some point in their lives (Hser et al., 2013). The women who experience co-occurring substance use and other mental health disorders are at increased risks of adverse life outcomes, such as poor psychosocial functioning, intimate partner violence, hospitalizations, health problems, and homelessness (Lipsky et al., 2010);
medication noncompliance; relapse; and suicidal behavior (Hser et al., 2013); criminal justice involvement (OAS, 2004); and, poorer treatment outcomes for women with substance use disorders and increased treatment dropout rates (Lipsky et al., 2010; Resko & Mendoza, 2012).

Analyzing mental health and substance use disorders in an aggregated manner is significant from the research, clinical and population health perspectives, evidenced by the Diagnostic and Statistical Manual (DSM-5) of Mental Disorders. Evidence indicating that individuals with mental disorders are more likely than individuals without mental health disorders to experience a substance use disorder (SAMHSA, 2016) coupled with the research finding that mental disorders, such as anxiety and depression, are the most prevalent mental disorders co-occurring with substance use disorders further support this grouping (Hser et al., 2015). Considering the co-occurrence of substance abuse and other mental health disorders, integrated systems of care treatment programs (SAMHSA, 2014), and the similarities of contextual risk factors that are parallel for both maternal substance use and mental health disorders, this dissertation study groups both conditions (i.e., substance-related disorders and other mental health disorders) together with respect to associated risks and consequences and describes differences when applicable.

Women with MD experience untoward social effects, including homelessness (Conners et al., 2004; Leonard et al., 2008), arrests (Conners, Johnson, & Whiteside-Mansell, 2009; Conners-Burrow et al., 2013; Leonard et al., 2008)), dependent and unstable housing (Hser et al., 2013), violence (Conners-Burrow et al., 2013; Perucci et al., 1991), and unemployment (Dvir, 2012). The lives of these women are characterized by single parenthood (Hser et al., 2013), as well as adverse social and environmental
circumstances that impact their health, familial relationships, and mothering capacity (David et al., 2012; Hecksher & Hesse, 2009; Jaser et al., 2011; Kauffman et al., 1997; Perera, Short & Fernbacher, 2014; Simmons et al, 2009).

Women with MD are more likely than their male counterparts to live with a partner with MD, and experience stressful interpersonal relationships (Kauffman et al., 1997; Caton et al., 2015). Women with substance abuse disorders are more likely than their male counterparts to have social networks containing a larger number of substance users, a higher incidence of sharing drug-injecting devices with more people in their social environment (Sherman, Latkin, & Gielen, 2001), and to be poly-drug users (Kauffman et al, 1997; Nelson-Ziupko et al., 1995). These women experience a greater severity of problems stemming from substance use than male users (Hecksher & Hesse, 2009).

Health effects for women with MD include stress (Jaser et al., 2011) and mental trauma related to physical and sexual abuse and concurrent psychiatric problems, e.g., post-traumatic stress disorder, suicide attempt, and other mood and anxiety disorders (Woodhouse, 1992). Women who experience trauma, including interpersonal and childhood sexual abuse, are highly represented in substance abuse samples (SAMHSA, 2014); up to 50-75% of women in substance abuse treatment have a history of physical and/or sexual abuse (Woodhouse, 1992).

Mental Health Among Children of Mothers with MD

The existing research literature provides evidence for links between maternal MD and untoward mental health outcomes for their children. Specifically, researchers show children of mothers with MD have increased likelihood of anxiety and depression
Researchers of a prospective cohort study among a random sample of 396 children and their substance-abusing mothers approximately 10 years after the mother’s admission to substance abuse treatment found that 22% of the children had total scores on the Child Behavior Checklist (CBCL; Achenbach, 1991) above the borderline or clinical cutoff (Hser et al., 2013). Elevated scores were more common in the externalizing domain (disruptive behaviors, including rule-breaking and aggressive behavior) whereas 24% of the children had scores in the borderline/clinical range than in the internalizing domain, where 16% of the children scored at or above the borderline/clinical cutoff. Researchers that collected data from 492 children from one-and-a-half to seven years old and their primary caregivers enrolled in a community-based intervention program aimed at mitigating the effects of violence exposure found that children of mothers with a history of substance use, but also mental illness, had significantly higher CBCL total scores (Risser et al., 2013), exhibiting more psychosocial dysfunction. Comparable findings in a study (VanDeMark et al., 2005) among 253 child participants of mothers with maternal MD, demonstrated these children had a three-fold increased likelihood (as compared to community samples) of scoring in the clinical range of emotional and behavioral problems.

Maternal mental illness is related to poor psychosocial wellbeing among children of mothers with mental health disorders. For example, researchers of an Australian cohort study with 816 children found that at age 15, children whose mothers had even a brief history of depression, were twice as likely to have depression as children whose mothers had no history of depression (Brennan, Le Brocque, &
Hammen, 2003). Jaser et al. (2011) provided evidence of an association between maternal depression and adolescent coping. The study demonstrated that adolescents of mothers with a history of depression used fewer primary control coping strategies, such as problem solving, emotional expression, and social support seeking (Jaser et al., 2011). These studies yielded results that support links between maternal MDs, specifically maternal depression, and child impaired functioning.

Parenting Practices among Mothers with MD

Mothers with MD have impaired parenting practices (Haggerty et al., 2008; Arria et al., 2012; Dvir, 2012; Perera et al., 2014). As stated previously, the literature on families affected by maternal MD is predominately deficit-focused, risk-based. Specifically, there is a link between parental MD and decreased parental monitoring and supervision (Latendresse et al., 2008; Stanger et al., 2004); poor quality parent-child interactions (Johnson, Cohen, Chen, Kasen, & Brook, 2006; Arria et al., 2012); parent-child conflict (Arria et al., 2012); less parental warmth; and inconsistent and harsh discipline (Stanger et al., 2004). These mothers may lack involvement in critical domains salient to adolescent behavior and development (Jaser et al., 2011; Suchman et al., 2007). Although the relationship between positive parenting and adolescent mental well-being is firmly established among the general population (Compas et al., 2010), this has been understudied among adolescents of mothers with MD.

Despite the multiple risk factors, adolescents of mothers with maternal MD can be resilient (Leonard et al., 2008; Criss et al., 2002), resistant to risky behaviors, and optimistic (Ronel & Levy-Cahana, 2011). Positive parenting partly contributes to this resiliency, as positive family functioning reduces negative outcomes among at-risk
adolescents (Prado et al., 2012). Extensive research on family-related protective factors for adolescents exists. Specifically, much of the existing evidence regards connectedness among family and between families as fostering positive opportunities and protection against risky behaviors (Prado et al., 2012) and poor mental health or behavior problems, thus playing a critical role in promoting the adolescent’s resiliency (Sale et al., 2003). However, scant research examines these factors among adolescents of mothers with maternal MD.

Positive parenting practices foster a healthy parent-child relationship and include parental warmth, support, monitoring, consistent communication and interaction with child, involvement in the child’s activities of life (Brown et al., 1993), and responsiveness (Dekovic & Meeus, 1997). Researchers found that positive parenting is a protective factor for adolescents (Brown et al., 1993; Prado et al., 2012) that has strong, beneficial impacts in the long term, leading to positive adolescent development (Tyler et al., 2008) with protection against internalizing and externalizing disorders (Coatsworth et al., 2000) and negative health outcomes (Prado et al., 2007). Positive parenting practices are associated with adolescent well-being, school engagement, and positive coping, and are inversely associated with the adolescent running away from home (Tyler et al., 2008).

Although there is relatively limited research on parenting-related protective factors for adolescents of mothers with MD, two studies suggest protective factors may be similar to the general population. Suchman et al. (2007) report that parent nurturance and involvement were significant predictors of the adolescent’s behavioral and psychological adjustment. Adolescents with mothers with substance-related disorders who were more involved in their life and engaged in positive parenting practices, such as
being less hostile and neglectful, reported less vulnerability to anxiety, depression, social stress, and atypical thoughts and a stronger internal locus of control, higher self-esteem, and closer interpersonal relationships (Suchman et al., 2007). Researchers who conducted a study with 454 adolescents of parents with mental health problems showed that parent’s availability, perceived parental support, and perception of being loved by parents protected the adolescent’s mental well-being (Olives et al., 2013). Researchers of these studies reviewed seem to suggest positive parenting practices had protective capacity on adolescent functioning and wellbeing. The proposed dissertation study extends the existing and relatively scant literature in this area by examining the relationships between parental involvement and positive parenting and adolescent mental health outcomes.

Self-Management among Adolescents Affected by Maternal MD

Research has an increased shift of focus toward examining self-management among adolescents. Self-management occurs in the context of risk and protective factors associated with a condition, the physical and social environment, as well as individual and family-level factors (Ryan & Sawin, 2009). The Individual and Family Self-Management Theory illustrates the processes involved in the utilization of knowledge and beliefs, self-regulation skills and abilities, and social facilitation to yield optimal health outcomes (UWM, 2011; Ryan & Sawin, 2009). The processes involved in the systematic utilization of knowledge and beliefs are self-efficacy, outcome expectancy, and goal congruence. Self-regulation skills and abilities are additional processes of self-management that involve goal setting, self-monitoring, emotional control, decision
making, self-evaluation, and reflective thinking. The process of social facilitation, an aspect of self-management, involves factors of influence, support, and collaboration. The self-management approach has been applied to various child populations living with chronic illnesses, including HIV (Denison et al., 2015), diabetes (Berg et al., 2014), asthma (Ahmad, E., & Grimes, 2011), autism (Carr, Moore, & Anderson, 2014; Koegel, Park, & Koegel, 2014), epilepsy (Lewis, Noyes & Hastings, 2014), ADHD (Bussing et al., 2016), and those at-risk for developmental disabilities (Bialas & Boon, 2010). However, limited research has been conducted to examine these self-management processes among adolescents of mothers with maternal MD.

Several studies have provided evidence of the association between self-regulation, a process of self-management, and adolescent outcomes (Hughes, Crowell, Uyeji, & Coan, 2012; Raffaelli & Crockett, 2003). While Raffaelli & Crockett (2003) found a relationship between decreased levels of self-regulation and negative behavioral outcomes among at-risk adolescents and Hughes, Crowell, Uyeji, & Coan (2012), found an association between poor self-regulation and family conflict, other researchers have focused on the relationship between self-management and positive outcomes (Moffitt et al., 2011). For example, Moffitt et al. (2011) found linkages of self-management with healthy behaviors. To date, limited research examines associations of self-management with mental wellbeing among adolescents of mothers with maternal MD. This study addresses this gap by examining self-management knowledge, beliefs, and behaviors and, self-regulation skills and abilities among adolescents in the context of the mother’s condition of maternal MD.
Clinical Challenges in Working with Families Affected by Maternal MD

There are considerable clinical challenges in working with families affected by MD. As outlined above, limited existing literature has examined linkages between individual and parent level protective factors and adolescent health outcomes that can yield implications for protective-focused interventions (Brennan, Brocque & Hammen, 2003). This gap in research has contributed to a dearth of research on clinical approaches to working with adolescents affected by maternal MD and scant evidence-based practices or guidelines for working with these at-risk youth. The implementation of a community-based clinical trial with adolescents and their families affected by maternal MD is challenging and requires ongoing problem-solving and strong academic-community collaboration. Despite these needs, inaccessibility to protective-focused, family support services for these children and families remain, further highlighting the urgency to focus on protecting and addressing the needs of these families. Such deficit-focused clinician biases hinder effective treatment strategies for these adolescents, contributing to service inequities and treatment disparities (Moskowitz et al., 2012; Surgeon General, 2001) and delay the adolescent seeking services so much so that by the time they come to the attention of service providers, they already have signs and symptoms of conduct or mental health problems. Families affected by MD need family-based assistance and support, particularly focused on building and nurturing resiliency (Hser et al., 2015).

The risk-based approaches that are typically used in research and clinical practice (Moskowitz et al., 2012; Services Administration, 2000; Hser et al., 2015) lead to a lack of understanding of strength-based treatments for families affected by MD. Focusing on
the protective factors of these families can be instrumental in increasing awareness of the strengths of these families, which may lead to optimal outcomes. This dissertation study focuses on protective factors at the child and parent levels as a means of informing strength-based preventative approaches for working with youth and families affected by MD.

A lack of qualitative methodologies is used in existing research studies among adolescents of mothers with maternal MD. Qualitative approaches that examine the perspectives of adolescents with maternal MD, who can offer valuable insight into their experiences and provide views of their self-management behaviors and processes using their voices, may lead to a better conceptual understanding to help inform intervention development. Maternal reports of mothers with MD about their children can be unreliable biased (Hser et al., 2015) and are typically negative (Hennigan et al., 2006). Furthermore, getting their opinions and allowing these adolescents to share their stories, uncontaminated by adult perspectives, provides them an opportunity to use their experiences to contribute to the development of protective-focused interventions.

Aims of the Dissertation

The overarching aim of the proposed dissertation is to examine multi-level adolescent-individual and adolescent-mother protective factors among adolescents of mothers with MD. This dissertation study examined protective factors, at the level of the individual child and at the level of parenting practices, for adolescents (ages 10-19 years) of mothers with MD, using quantitative and qualitative methods approaches. The quantitative portion performed a secondary data analysis using baseline data from an ongoing randomized trial, SET-Recovery/Healthy Home. The purpose of SET-
Recovery/Healthy Home is to test the relative efficacy of an intervention, named “Healthy Home,” derived from Structural Ecosystems Therapy (SET; Mitrani, Robinson, & Szapocznik, 2009; Mitrani et al., 2012) aimed at improving the health of mothers with MD and their children, preventing relapse, and improving family relationships. Interviews with adolescents whose mothers have participated in the SET-Recovery/Healthy Home study informed the qualitative portion of the dissertation.

Theoretical Frameworks

Two theoretical frameworks, Ecodevelopmental Theory (Prado et al., 2012) and the Individual and Family Self-Management Theory (Ryan & Sawin, 2009), guided the dissertation study. Ecodevelopmental Theory was influenced by Bronfenbrenner’s conceptualization of social ecology of human development and highlights the interrelationship and transitional nature of contexts of family and the pivotal social domains to individual development and mental health beyond family, which include the microsystem (direct interactions of family and peer), mesosystem (transactions between parent and peer), exosystem (indirect influences), and macrosystem-level (broad social/cultural influences) (Bronfenbrenner, 1979; Szapocznik & Coatsworth, 1999). This dissertation study applied Ecodevelopmental Theory by examining the mother and adolescent’s microsystems and the mother-adolescent exosystem. The impact of the mother exosystem and adolescent microsystem (e.g. adolescent-mother/parent relations) on child internalizing and externalizing outcomes were examined in the quantitative portion of the study. The impact of the adolescent microsystem as well as other aspects of the adolescent’s ecology were examined in the qualitative portion of the study.
This dissertation study also applied the Individual and Family Self-Management Theory to examine how the adolescent applied internal resources of self-management and self-regulation strategies to help him or her navigate daily challenges, a context understudied in the literature with this population. The qualitative portion of the study explored such internal resources of the adolescent in coping with adversities.

Figure 1 illustrates the integration of the Ecodevelopmental and Individual and Family Self-management theories as applicable to this dissertation study. This model was proposed among adolescents of mothers with maternal MD as it illustrates the salient, multi-level factors and resources at the adolescent-individual and maternal/parenting levels that lead to proximal and distal outcomes of wellbeing. Both the self-management and maternal/parenting factors occur in the context of risk and protective factors specific to mother’s distress.

The dissertation is organized into three manuscripts to be submitted for peer-reviewed publication. This first chapter provides a general background and review related to the research problem and goals of the dissertation. Chapters Two to Four consist of the individual manuscripts that will be submitted for publication. Chapter Five summarizes the results of the dissertation, provides a discussion that integrates the three manuscripts, and outlines future research that builds upon the integrated findings. A manuscript integrating the quantitative and qualitative findings will be developed in the future; it will be outside the scope of the dissertation.

Specific Aims and Abstracts

The dissertation has three Specific Aims, one for each of the manuscripts to be submitted for publication.
SPECIFIC AIM 1. To examine the relationships between maternal/parenting factors, adolescent internalizing (e.g. anxiety-withdrawal) and externalizing problems (e.g. conduct disorder and socialized aggression) among adolescents (ages 10-17) of mothers with MD. The manner in which this aim was achieved is presented in Chapter Two of the dissertation titled, “Parental Involvement as a Protective Factor among Adolescents of Mothers with Mental Disorders.” Using baseline data (as reported by the mother) collected in the parent randomized trial, SET-Recovery/Healthy Home, this study tested the relationships between mother’s distress (a latent variable composed of stress, anxiety, and depression), mother’s substance use, positive parenting practices (a scale composed of parental involvement and positive parenting subscales) and the adolescent’s internalizing and externalizing problems. Figure 2 illustrates all direct and indirect relationships examined in the model.

Hypothesis 1: Mother’s mental health will be related to adolescent internalizing and externalizing problems.

H1a: Mother’s distress will be related to adolescent internalizing problems.
H1b: Mother’s substance use will be related to adolescent internalizing problems.
H1c: Mother’s distress will be related to adolescent externalizing problems.
H1d: Mother’s substance use will be related to adolescent externalizing problems.

Hypothesis 2: Mother’s mental health will be related to positive parenting practices.

H2a: Mother’s distress will be related to parental involvement.
H2b: Mother’s substance use will be related to parental involvement.
H2c: Mother’s distress will be related to positive parenting.
H2d: Mother’s substance use will be related to positive parenting.
Hypothesis 3: Mother’s positive parenting practices will be inversely associated with adolescent internalizing and externalizing problems.

H3a: Mother’s parental involvement will be related to adolescent internalizing problems.

H3b: Mother’s positive parenting will be related to adolescent internalizing problems.

H3c: Mother’s parental involvement will be related to adolescent externalizing problems.

H3d: Mother’s positive parenting will be related to adolescent externalizing problems.

Hypothesis 4: Mother’s positive parenting practices will mediate the relationship between mother’s distress and adolescent internalizing and externalizing problems.

Hypothesis 5: Mother’s positive parenting practices will mediate the relationship between mother’s substance use and adolescent internalizing and externalizing problems.

SPECIFIC AIM 2: To gain an understanding of adolescents’ individual-level resources that may help to mitigate the negative effects of maternal MD. The manner in which this aim was achieved is presented in Chapter Three of the dissertation titled, “Living with a Mother with a Mental Disorder: Self-Management of Adolescents as a Protective Factor.” The Principal Investigator (PI) of this dissertation, who serves as research assistant and clinician on SET-Recovery/Healthy Home, interviewed adolescents between the ages of 10 and 19 whose mothers currently or previously participated in the parent study. Interview questions were aimed at exploring the adolescent’s self-management resources as well as family and environmental factors that
help the adolescent to manage adversities in life. The Individual and Family Self-
Management Theoretical Framework served as the basis for the interview questions,
which were guided by the following research questions:

1. What are the self-managing knowledge and beliefs among adolescents whose
   mothers have MD?

2. What are the self-management behaviors among adolescents whose mothers have
   MD?

SPECIFIC AIM 3: To describe the challenges, problem-solving approaches, and
lessons learned of conducting community-based, family research among mothers with
MD and their children. The manner in which this aim was achieved is presented in
Chapter Four of the dissertation titled, “Community-Based Research with Families of
Mothers with a Mental Disorder: Lessons Learned.” The goal of this chapter is to present
methodological and logistical challenges encountered while conducting our research, a
community-based clinical trial testing the effectiveness of a home-based family-
strengthening intervention for mothers with MD and their children and an ancillary study
conducting qualitative interviews with a subset of the youth in the clinical trial. The
information sources for this report included meeting notes, IRB modifications, study
enrollment and contact logs and reports, and community agency contact notes. The
analysis for this report began with reviewing all IRB protocol modifications since these
typically reflected changes to the protocol in response to challenges and the other data
sources mentioned above. The report identified challenges related to 1) participant
recruitment and retention, 2) participant burden, 3) participant service needs, 4)
community provider engagement, and 5) protection of vulnerable participants.
Approaches to managing these challenges included adapting the study protocol to fit with participant needs and agency operations, fostering ongoing mutual collaborations, and piloting and documenting procedures. Ethical issues surrounding conducting research among these families are also discussed.

The integration of the qualitative and quantitative data for Chapter 5 is accomplished by comparing both forms of data addressing specific aims 1: relationship between mother’s report of her distress (stress, anxiety, and depression), substance use, and positive parenting practices, and child internalizing and externalizing problems, and specific aim 2: adolescent interviews focused on adolescent-individual level resources of self-management, self-regulation (e.g. emotional control) and social facilitation, which include parenting practices, for convergence to examine similarities and discrepancies between mother and child reports. A future manuscript for publication will aim to develop a conceptual model for working with adolescents affected by MD that is guided by Ecodevelopmental and Individual and Family Self-Management theories and rooted in this data. This step will help inform future intervention development efforts focused on multi-level protective factors tailored to adolescents and their families.

Few studies have investigated the protective processes of positive parenting and self-management and their associations in the context of adolescents of mothers with maternal MD. Ultimately, the goal of the dissertation is to help researchers and clinicians to 1) be better informed of adolescent protective processes, 2) recognize, validate, and strengthen self-managing protective behaviors among adolescents of mothers with MD, 3) develop and implement effective adolescent-centered treatment strategies tailored to
the adolescent’s protective capacities, and 4) provide guidance to clinicians to overcome challenges of working with families affected by maternal MD.
CHAPTER 2: PARENTAL INVOLVEMENT AS A PROTECTIVE FACTOR AMONG ADOLESCENTS OF MOTHERS WITH MENTAL DISORDERS

Background

Women are disproportionately affected by mental disorders (MD) (World Health Organization, 2016; National Institute of Health [NIH], 2016), which represent a large burden for women worldwide (NIH, 2016; Whiteford et al., 2015) as well as adverse consequences for their families (Conners-Burrow et al., 2013; Hser et al., 2013; VanDeMark et al., 2005). According to the National Survey on Drug Use and Health, more than 3 million women of childbearing age experience MD (Substance Abuse and Mental Health Services Administration, 2012). Additionally, a national survey indicates that approximately 1 in 2 women of child-bearing age (i.e., aged 18–44 years) uses psychoactive substances, such as illicit drugs or alcohol (Women’s Health, 2014). An estimated 5.7% of females 12 years and older abuses substances (SAMHSA, 2012), and females constitute more than 50% of the 2.4 million Americans using prescribed medications for nonmedical reasons for the first time within the previous year (NIDA, 2011). According to the findings of the Treatment Episode Data Set (TEDS), pregnant females aged 15 to 44 years accounted for 63.8% of substance abuse treatment admissions, and non-pregnant females aged 15 to 44 years accounted for 49.1% of admissions in 2010 (SAMHSA, 2013c).

Mental illness is projected to be the leading cause of disability by 2030 (World Health Organization, 2011). Mental health problems, such as depression, anxiety, post-traumatic stress, and bipolar disorder, represent health disparities that are prevalent among women, many of whom are of childbearing age (SAMHSA, 2013a; SAMHSA, 2013b). According to the findings of the National Survey on Drug Use and Health 2012 report,
women constituted 29.4 million of the ambulatory care visits with a primary mental health diagnoses between 2005 and 2008, as compared to 18.5 million visits for men (SAMHSA, 2014). In 2007, women accounted for two-thirds of users of mental health services (Atkins, 2010). Given that approximately 8.4% of women will experience depression, as compared to 5.2% of men who will experience this condition in any given year, women are almost twice as likely as men to experience depression (Atkins, 2010; SAMHSA, 2013).

Empirical evidence exists for the harmful effects of maternal MD on children’s health (Conners-Burrow et al., 2013; Hser et al., 2013; VanDeMark et al., 2005). These harmful effects may be due to disruptions in parenting (Arria et al., 2012; Dvir, 2012; Haggerty et al., 2008; Perera et al., 2014), interruptions in social support, family separation related to loss of maternal custody, neglect (Kohl et al., 2011; Atkins, 2010), decreased parental monitoring and supervision (Latendresse et al., 2008; Stanger et al., 2004), and/or problematic parent-child interactions (Arria et al., 2012; Johnson, Cohen, Chen, Kasen, & Brook, 2006; Stanger et al., 2004). Nationwide calls to protect these families are in effect (Surgeon General, 2016) given the array of risks confronting women with MD as well as their children, whom the majority of these women are caring for by themselves (Osborne & Berger, 2009).

Despite their multiple risk factors, children of mothers with MD can be resilient (Criss et al., 2002; Leonard et al., 2008), resistant to risky behaviors, and optimistic about living a better future (Ronel & Levy-Cahana, 2011). Research among mothers with MD and their children identifies the family as a potential buffer against mental, emotional, and physical health infirmities (Bell, 2012; Pequegnat & Stover, 2000). Recent work has examined the protective factors, i.e., resilience, that exist in the context of adversity and
have the potential to influence adaptation to life stressors and the attainment of wellness (Feder et al., 2009). Resilience is conceptualized as “the ability of individuals to be tested by adversity and continue to demonstrate adaptive psychological and physiological stress responses” (Feder et al., 2009). Extensive research demonstrates that connectedness among family fosters protection against risky behaviors (e.g. unsafe sexual behavior) and mental disorders, including illicit substance use (Prado et al., 2010) and thus, plays a critical role in promoting the adolescent’s resiliency (Sale et al., 2003). However, scant research examines these factors among adolescents of mothers with MD.

Positive parenting practices include parental warmth, support, monitoring, consistent communication and interactions with their child, and involvement in the child’s activities of life (Brown et al., 1993) and responsiveness (Dekovic & Meeus, 1997). Research has found that positive parenting is a protective factor for adolescents (Brown et al., 1993; Prado et al., 2010) that has strong, beneficial impacts in the long term, leading to positive adolescent development (Tyler et al., 2007). Positive parenting has been shown to protect against internalizing and externalizing disorders (Coatsworth et al., 2000) and negative health outcomes (e.g. illicit substance use and unsafe sexual behavior) (Prado et al, 2007). Positive parenting practices are associated with adolescent well-being, school engagement, and positive coping and inversely associated with the adolescent running away from home (Tyler et al., 2008).

Although there is relatively little research on parenting-related protective factors for adolescents of mothers with MD, two studies suggest similarities to the general population. Suchman and colleagues (2007) showed that parental nurturance and involvement were significant predictors of the adolescent’s behavioral and psychological
adjustment of adolescent children of 98 women in substance use treatment. Mothers with substance use disorders who were more involved in their adolescent children’s lives and engaged in positive parenting practices, such as being less hostile and neglectful, were reported to have children who were less vulnerable to anxiety, depression, social stress, and atypical thoughts (Suchman et al., 2007). Additionally, these adolescents reported a stronger internal locus of control, higher self-esteem, and closer interpersonal relationships (Suchman et al., 2007). Researchers of a study with 454 adolescents of parents with mental health problems, including anxious and depressive symptoms (e.g. disturbances in peacefulness and feeling sad), showed that parent’s availability, perceived parental support, and perception of being loved by parents protected the adolescent’s mental well-being (Olives et al., 2013). The current study extends the existing and relatively scant literature in this area by examining maternal parenting specific to the context of adolescent children of mothers with mental disorders.

Theoretical Framework

Ecodevelopmental Theory (Prado et al., 2010) guided the study. Ecodevelopmental Theory was influenced by Bronfenbrenner’s conceptualization of social ecology of human development and highlights the interrelationship and transitional nature of contexts of family and the pivotal social domains to individual development and mental health beyond family, which include the microsystem (direct interactions of family and peer), mesosystem (transactions between parent and peer), exosystem (indirect influences), and macrosystem-level (broad social/cultural influences) (Bronfenbrenner, 1979; Szapocznik & Coatsworth, 1999). The study applied Ecodevelopmental Theory by examining the adolescent-mother microsystem interaction
and the indirect influence of the mother’s exosystemic factors (psychological distress and substance use) on the adolescent’s internalizing and externalizing outcomes (see Figure 2).

Study Aims and Hypotheses

The overarching aim of the current study was to examine the protective impact of maternal positive parenting practices on adolescent mental wellbeing (internalizing and externalizing problems) among adolescents of mothers with MD. The study tested relationships between the predictors of mother’s psychological distress (a latent variable composed of stress, anxiety, and hassles); mother’s substance use; positive parenting practices (a scale composed of parental involvement and positive parenting); and the outcomes of child internalizing (e.g. anxiety-withdrawal) and externalizing problems (e.g. conduct disorder and socialized aggression). Figure 2 illustrates all direct and indirect relationships examined in the model. It was hypothesized that:

Hypothesis 1: Mother’s mental health will be related to adolescent internalizing and externalizing problems.

H1a: Mother’s distress will be related to adolescent internalizing problems.

H1b: Mother’s substance use will be related to adolescent internalizing problems.

H1c: Mother’s distress will be related to adolescent externalizing problems.

H1d: Mother’s substance use will be related to adolescent externalizing problems.

Hypothesis 2: Mother’s mental health will be related to positive parenting practices.

H2a: Mother’s distress will be related to parental involvement.

H2b: Mother’s substance use will be related to parental involvement.
H2c: Mother’s distress will be related to positive parenting.

H2d: Mother’s substance use will be related to positive parenting.

Hypothesis 3: Mother’s positive parenting practices will be inversely associated with adolescent internalizing and externalizing problems.

H3a: Mother’s parental involvement will be related to adolescent internalizing problems.

H3b: Mother’s positive parenting will be related to adolescent internalizing problems.

H3c: Mother’s parental involvement will be related to adolescent externalizing problems.

H3d: Mother’s positive parenting will be related to adolescent externalizing problems.

Hypothesis 4: Mother’s positive parenting practices will mediate the relationship between mother’s distress and adolescent internalizing and externalizing problems.

Hypothesis 5: Mother’s positive parenting practices will mediate the relationship between mother’s substance use and adolescent internalizing and externalizing problems.

The aims in the present study reflect areas central to the lives of adolescents and their mothers with MD (positive mother-child relationships) that provide a focus on protective factors that may buffer these adolescents and mothers from a poor quality of life marked with negative outcomes that interfere with their wellbeing, including disruptions in family functioning.
Methods

Design

This study was a secondary analysis of baseline data from an ongoing randomized clinical trial called SET-R (Structural Ecosystems Therapy for Women in Recovery), which tests a nurse-led family-strengthening intervention, *Healthy Home*, that is derived from Structural Ecosystems Therapy (SET; Mitrani et al., 2012) aimed at the following: 1) improving the health of mothers in substance abuse/mental health recovery, 2) preventing relapse, 3) improving the health of the children, and 4) improving family relationships that support the mother’s recovery and mother/child health. SET-Recovery has assessment timepoints at a pre-intervention baseline as well as 4, 8, and 12 months post-enrollment; it collects data from the mother regarding, but not limited to, the mother’s substance use (e.g. recent alcohol intoxication and illicit substance use), stressors (e.g. hassles intensity), mental health (e.g. anxiety and depression), and positive parenting practices. Mothers report on the wellbeing of their children in terms of the child’s internalizing (e.g. anxious/depressed, withdrawn, and somatic) and externalizing (e.g. rule breaking and aggression behavior) problems. The current study extends the aims of the parent study by examining parenting factors as possible mediators of the relationship between mothers’ mental health and their adolescent children’s wellbeing.

Using baseline data from the parent study, the current study used a quantitative approach to examine the relationships between the latent variable, mother’s psychological distress, and the parental protective factors, positive parenting practices, to child internalizing and externalizing problems. Demographic variables (gender, age, race/ethnicity) were included as control variables. The University of Miami’s
Institutional Review Board approved procedures for this study and the parent study.

Participants and Setting

The parent clinical trial is a community-based study with mothers recruited from among various agencies (but predominantly from a single agency) that serve women with MD. Participant recruitment, outreach, consent and data collection for the parent study were conducted by a research team employed by the community partner for the study, Banyan Health Systems, and overseen by the parent study’s principal investigator. The study intervention, Healthy Home, was delivered by nurses employed by the community partner.

Sample

The participants enrolled in the parent study were 172 mothers in outpatient substance abuse/mental health treatment and/or case management and their children, ages 2-18 years. The parent study completed all data collection; specifically, baseline data in August, 2016. Study staff invited all mothers enrolled in substance abuse, mental health treatment, or case management at treatment facilities in a large, urban area who had minor children to participate in the parent study. The ethnic breakdown of women receiving outpatient substance abuse/mental health treatment services at the treatment site where a majority of women were clients was 66% Hispanic, 24% Black, and 10% White, non-Hispanic. The SET-Recovery’s sample comprised 81% Hispanic, 9% Black, and 4% White, non-Hispanic, and 6% Other.

Mothers in the parent study with children ages 10-17 years were included in the analysis for this study. The sample for this study included 90 mothers and 118 children of these mothers. Tables 1 and 2 show the characteristics of the mothers and children in
the study. The age group of 10-17 years is a critical time period for psychosocial and physiological developmental transition (Pantin et al., 2004). The current study acknowledges that children aged 10-12 years are considered preadolescents (National Resource Center, 2009) and 10-17 is a wide age range; the study refers to those aged 10-17 as “adolescents.”

Inclusion/Exclusion Criteria. Mothers were eligible for the parent study if they:
(1) were enrolled in outpatient substance abuse/mental health treatment or case management, (2) had at least one minor child with whom they have at least monthly contact, (3) were at least 18 years old, (4) were capable of giving informed consent and comprehending either English or Spanish, and (5) were willing and able to participate fully in the protocol.

Procedures

Recruitment and Screening. Recruitment and screening of mothers was handled by the parent study; no additional recruitment and screening of mothers were needed for this study. The principal investigator and research team created partnerships with staff at various outpatient and inpatient mental health and substance use agencies throughout a large urban area to facilitate participant recruitment.

Measures

In the parent study, all instruments were delivered to the mother in interview format, typically in the participant’s home. All of the measures are standardized instruments that have been used in previous research with similar populations, and were in English and Spanish. All have established scoring procedures. Mothers completed the
measures in their language of choice. Mothers received $50 for the baseline assessment interview to cover time and travel expenses.

Demographics. Demographic information was obtained from a questionnaire completed by mothers, including questions regarding the mother’s age, race/ethnicity, monthly income, educational history, birthplace, type of mental health/substance treatment, mental or substance related diagnosis as well as the adolescent’s age, gender, race/ethnicity, living status (with or without the mother), grade in school, birth country, and language he/she understands better.

Internalizing and Externalizing Problems were measured using the Child Behavior Checklist (CBCL; Achenbach, 2001) in which mothers rated their children’s emotional and behavioral problems. Conduct disorder and socialized aggression subscales were combined into an externalizing behaviors scale. The anxiety-withdrawal subscale served as a measure of internalizing behaviors. Previous research with families affected by maternal substance use has shown strong reliability in both subscales (α=. 95, α=.81, respectively; Mitrani et al., 2010). Raw scores were used in this study. Cronbach’s alpha for this study indicated excellent reliability for both subscales, externalizing (31 items, α=. 92) and internalizing (32 items, α=.91). Example items from the externalizing subscale included “drinks alcohol without parents’ approval” and “runs away from home.” Example items from the internalizing subscale included “feels worthless or inferior” and “unhappy, sad or depressed.”

Positive Parenting Practices were assessed using the Parenting Practices questionnaire (mother form) (Gorman-Smith, Tolan, Zelli, & Huesmann, 1996) based on items from the Pittsburgh Youth Survey (Thornberry, Huizinga, & Loeber, 1995).
Parental involvement and positive parenting were assessed using the corresponding subscales from the Parenting Practices Questionnaire – mother form (Gorman-Smith, Tolan, Zelli, & Huesmann, 1996). These subscales have shown acceptable reliability in previous research with families affected by maternal substance abuse: parental involvement (20 items, \( \alpha = .80 \), Mitrani et al., 2010) and positive parenting (9 items, \( \alpha = .68 \), Mitrani et al., 2010). Cronbach’s alpha demonstrated good reliability for this study: parental involvement (12 items, \( \alpha = .84 \)) and positive parenting (6 items, \( \alpha = .84 \)). Example items from the parental involvement subscale include “when was the last time that you discussed with…his/her plans for the coming day” and “about how often have you discussed with …his/her plans for the coming day.” Example items from the positive parenting subscale include “in the past month when …did something that you liked or approved of, how often did you give him/her a wink or smile” and “in the past month when …did something that you liked or approved of, how often did you give him/her a hug, a pat on the back, or a kiss for it.” All items on both subscales were evaluated on a 7-item Likert scale (Never, Hardly ever, Sometimes, Usually, Always, Don’t know, and Refused), except for two items on the parental involvement subscale that were evaluated on a 7-item Likert scale with responses: More than 1 month ago, Within the last month, Within the last week, Yesterday, Never, Don’t Know, and Refused. For this study, parental involvement and positive parenting had binary distributions, each dichotomized (0= none; 1=yes) to correct for skewness.

*Mothers’ Substance Use* was assessed using the Addiction Severity Index (ASI), which measures the severity of possible treatment problems in multiple facets frequently impacted by substance use disorders (\( \alpha > .70 \)). The ASI asks about the quantity of use of
alcohol to the point of intoxication and other illicit drugs in the past 30 days (McGahan et al., 1986). For this study, ASI questions related to alcohol intoxication and illicit substance use in the past 30 days were dichotomized (0=no endorsement; 1=any endorsement) then combined into a single variable to represent the level of recent use of alcohol to the point of intoxication and illicit drug use that was also dichotomized (0=no endorsement; 1=any endorsement).

Mother’s Psychological Distress was a latent variable, tested as part of this analysis, composed of the following measures:

*Stress* was assessed using the Hassles Scale, a Likert-type scale that assesses hassles (DeLongis, Folkman, & Lazarus, 1988). The study used the hassle intensity, the cumulative severity divided by the frequency of a subset of 23 items related to partner and family relationships, personal and family health, finances and mental health. A similar subset of items was used successfully with HIV+ women in substance abuse recovery (α > .70, Mitrani et al., 2012). All responses were evaluated on a 4-item Likert scale (None, Somewhat, Quite a bit, and Great deal).

*Anxiety and Depression* were assessed using the PROMIS Anxiety and Depression scale (Pilkonis et al., 2011). The scale measures facets, including sadness, irritability, moodiness, and negative and positive affect. For this study, T-score transformations of raw scores were used. The measure developers reported good reliability (depression, α =.98; anxiety, α =.97; Pilkonis et al., 2011). Cronbach’s alpha demonstrated excellent reliability for this study: depression, α = .93 and anxiety, α = .95.
Analyses

*Power Analysis.* A power analysis conducted with G*power indicated that data from 77 mothers would be sufficient (α = .05; power = .80) to test the study hypotheses, direct effects. The parent study enrolled 172 mothers. If 45% of mothers enrolled in the parent study had children within the 10-17 years age range, there was 80% power to detect medium size effects. This study consisted of 90 mothers.

*Preliminary Analyses.* Descriptive analyses described the sample. Distributions and frequencies of all measures were examined for non-normality and transformed as needed. Variable transformation for anxiety, depression, hassle intensity, substance use, positive parenting and parental involvement were used in the analyses. Mother’s psychological distress was modeled and tested as a latent factor. The appropriateness of the study’s operational definition of mother’s distress was tested using a confirmatory factor analysis (CFA) to show fit of the identified components of a theoretically-conceived latent mother’s distress variable (stress, anxiety, and hassle intensity). The WLSMV (weighted least squares) estimation allowed for modeling with dichotomous, ordered categorical and continuous latent variable indicators, regardless of missing data patterns (Muthén, 1984) and was robust to standard errors (Hox et al., 2010). Model fit was evaluated in terms of the comparative index (CFI), the root mean square error of approximation (RMSEA), and the chi-square statistic. CFI values of greater than or equal to .95, RMSEA values equal to or less than .02, and a non-significant (p > .05) chi-square indicate good model fit (Byrne, 2001).

*Hypotheses Testing.* Hypotheses 1 through 5 were tested with SEM in Mplus, 7 (Muthén & Muthén, 2012). Indirect effects were tested using a 95% confidence interval
Mplus allowed for outcome variables with distributions that are not continuous (e.g., Poisson for skewed variables or logistic for binary outcomes), which is particularly important with substance use and health outcomes and for clustering (i.e., mothers with multiple children were not independent).

Results

Preliminary Analyses

Descriptives. Mothers reported adolescent’s internalizing problems ($M = 14.12; SD = 11.62$) and externalizing problems ($M = 12.09; SD = 11.60$). Mother’s anxiety ($M = 62.65; SD = 12.78$), depression ($M = 58.09; SD = 11.00$), and hassle intensity ($M = 3.45; SD = 1.49$) were assessed. Mother’s anxiety and depression T-score means were not clinically elevated, as clinical cutoff are T-score is $> 60$. Eighty-seven (96.7%) mothers reported no recent alcohol use to intoxication (in the past 30 days) while three (3.3%) mothers reported recent alcohol use to intoxication (in the past 30 days). Eighty-five (94.4%) mothers reported no recent illicit use (in the past 30 days) while five (5.5%) mothers reported recent illicit use (in the past 30 days). About 54% (54.2%) of parenting reports were high levels of positive parenting. About 51% (50.8%) of parenting reports were high levels of parental involvement.

Potential Control Variables. As part of the preliminary analyses, the relationships between demographic variables (such as adolescent’s gender and mother’s age and race/ethnicity), child internalizing and externalizing problems, and positive parenting and parental involvement were investigated. Results from this preliminary model indicated no statistically significant paths; thus, these demographic variables were not used in models for later hypothesis testing.
Latent Psychological Distress. The three-variable model for psychological distress was saturated, $\chi^2 (df = 11) = 10.33, p = .501$, $CFI = 1.00$ and $RMSEA < 0.001$. All three indicators of mother’s psychological distress loaded significantly and strongly onto the single latent construct: anxiety, $B = 0.75, SE = 0.10, \beta = .90, p < .001$, $95\% CI [0.55, 0.95]$, depression, $B = 0.69, SE = 0.09, \beta = .93, p < .001$, $95\% CI [0.52, 0.87]$ and hassle intensity, $B = 0.72, SE = 0.14, \beta = .52, p < .001$, $95\% CI [0.43, 1.00]$. These significant loadings suggest good model fit (Byrne, 2012). The latent variable explained 82% of the variance in anxiety, 87% in depression, and 27% in hassle intensity. Figure 3 demonstrates results of the hypothesized SEM model in predicting mental problems. Modeled relationships explained 26% and 25% variance in adolescent internalizing problems and adolescent externalizing problems, respectively.

Hypothesis 1: Relationship Between Mother’s Mental Health and Adolescent Mental Health

Mother’s psychological distress was significantly related to the adolescent’s internalizing problems, $B = 4.33, SE = 1.29, \beta = .37, p = .001$, $95\% CI [1.82, 6.85]$. Mother’s substance use was significantly related to adolescent’s externalizing problems, $B = 11.54, SE = 4.39, p = .009, \beta = .28$, $95\% CI [2.94, 20.15]$. There was no significant relationship between the mother’s substance use and internalizing problems, $B = 0.97, SE = 3.93, \beta = .02, p = .805$, $95\% CI [-6.73, 8.67]$. There was no significant relationship between the mother’s distress and adolescent externalizing problems, $B = -0.88, SE = 0.93, p = .344, \beta = -.08$, $95\% CI [-2.70, 0.94]$.

Standardized coefficients for the relationships between mother’s psychological distress and substance use, positive parenting practices, and adolescent mental wellbeing are presented in Table 3.
Hypothesis 2: Relationship Between Mother’s Mental Health and Parenting Practices

None of the relationships tested in hypothesis 2 were significant. There was no significant relationship between the mother’s psychological distress and parental involvement, $B = 0.03$, $SE = 0.15$, $p = .845$, $\beta = .03$, 95% CI [-0.27, 0.32], between mother’s substance use and parental involvement, $B = -0.21$, $SE = 0.50$, $\beta = -.06$, $p = .675$, 95% CI [-1.20, 0.77], between the mother’s psychological distress and positive parenting, $B = 0.09$, $SE = 0.16$, $\beta = .09$, $p = .586$, 95% CI [-0.23, 0.40] or between mother’s substance use and positive parenting, $B = 0.14$, $SE = 0.55$, $p = .805$, $\beta = .04$, 95% CI [-0.94, 1.21].

Standardized coefficients for the relationships between mother’s psychological distress and substance use, and positive parenting practices are presented in Table 4.

Hypothesis 3: Relationship between Mother’s Parenting Practices and Adolescent’s Mental Health

There was a significant relationship between parental involvement and adolescent internalizing problems, $B = -4.53$, $SE = 1.59$, $p = .004$, $\beta = -.39$, 95% CI [-7.66, -1.41] and with adolescent externalizing problems, $B = -5.38$, $SE = 1.52$, $p < .001$, $\beta = -.47$, 95% CI [-8.36, -2.41]. There was no significant relationship between positive parenting and adolescent internalizing problems, $B = 0.97$, $SE = 1.67$, $p = .563$, $\beta = .08$, 95% CI [-2.31, 4.24] or with adolescent externalizing problems, $B = 1.78$, $SE = 1.60$, $p = .264$, $\beta = .16$, 95% CI [-1.35, 4.92].

Standardized coefficients for the relationships between mother’s psychological distress and substance use, positive parenting practices, and adolescent mental wellbeing are presented in Tables 3 and 4.
Hypotheses 4 and 5: Mediation Effects of Parenting Practices

There was no relationship between mother’s psychological distress and parenting or between mother’s substance use and parenting; thus, there was no test for mediation of the parenting practices on adolescent internalizing and/or externalizing problems (Baron & Kenny, 1986).

Discussion

The results of this study supported the relationship between maternal mental health and child mental health, specifically, the mother’s psychological distress was related to the adolescent child’s internalizing problems, and the mother’s substance use was related to the adolescent child’s externalizing problems. First, these findings are consistent with other studies that have found mental health risk among children of mothers with MD. For example, researchers found children of mothers with MD have increased likelihood of disruptive and oppositional behavior (VanDeMark et al., 2005).

Possible explanations of these findings include 1) an underlying biological or environmental susceptibility that affects both mother and child, 2) a causative link between symptoms of the mother’s MD and child mental health problems, or 3) reciprocal processes in which the child’s problems exacerbate the mother’s mental health problems. For example, researchers Caspi et al. (2002) illustrated environmental pathways as mechanism of linkages to MD supporting environmental capacity to influence MD. Additionally, researchers Kendler et al. (2012) found that, in addition to environmental influences, genetic factors increase risk to MD and deleterious effects of negative environmental experiences associated with MD. Moreover, previous evidence confirms reciprocal processes exist between MD and environment, including the family
The effect regarding reciprocal processes could be examined in a longitudinal study.

Second, parental involvement, although not positive parenting, was inversely related to adolescent internalizing and externalizing problems. The protective effects of parental involvement found in this study is consistent with extensive research of at-risk adolescent populations (Olives et al., 2013; Suchman et al., 2007). Moreover, parental involvement had a stronger relationship with the adolescent internalizing problems ($\beta = -.39$) and externalizing problems ($\beta = -.47$) than mother’s psychological distress with adolescent internalizing ($\beta = .37$), and mother’s substance use with adolescent externalizing problems ($\beta = .28$). This relative strength of relationships lends support to the potential benefits of interventions that are designed to increase parental involvement for adolescents with mothers who have MD.

Contrary to previous research in which MD had a negative impact on parenting practices (Oyserman, 2002), the findings of this study supported the notion that the mother’s psychological distress and substance use was unrelated to her parenting practices. These findings suggest that an alternate mechanism other than the mother’s MD, not tested in this study, impacts the mother’s parenting practices. Additional suggestions include: 1) mothers with MD can parent as effectively as mothers without MD, 2) the parenting measure was not sensitive to disruptions in parenting, and 3) mothers in this sample did not have high enough symptoms to observe the disruption on parenting. Future research should examine other drivers of parenting processes not tested here, such as social support or the presence of other parental figures (e.g. father, etc.).
There are limitations in the current study which warrant caution in interpreting the results. First, the data collected in the study was solely mother-reported and thus, subject to reporter bias. Mothers with MDs may be more likely to recall maladaptive behaviors of their adolescent children (Downey & Coyne, 1990), which could explain the relationship between mother’s psychological distress and internalizing. However, it is noteworthy that psychological distress was not related to the mother’s report of child externalizing. Second, the study employed a cross-sectional design, thus, directionality or reciprocity of relationships could not be tested. Lastly, the wide age range of (10-18) may mask the effect of developmental aspects/transitions of early, middle, and late adolescence and their impact on adolescent mental health outcomes.

Limitations notwithstanding, this study is one of very few that used a strength-based approach to investigate associations between maternal mental health, parenting practices, and adolescent mental wellbeing in terms of internalizing and externalizing problems.

Implications for Research and Practice

The findings from this study indicate that promoting parental involvement in the lives of at-risk adolescents, specifically those whose mother has a mental disorder, may bolster adolescent mental wellbeing. Also, it is important for providers working with mothers with MD and their children to recognize mental health related stressors on mothers so that appropriate resources are provided to parents in order for more attention to be given to the adolescent (Prado et al., 2010).
CHAPTER 3: LIVING WITH A MOTHER WITH A MENTAL DISORDER: SELF-MANAGEMENT OF ADOLESCENTS AS A PROTECTIVE FACTOR

Background

Maternal mental disorders (MD), including substance use, are significant public health problems affecting adolescent health. Millions of women, many of whom are of childbearing age, are affected by MD despite intervention efforts (Substance Abuse and Mental Health Service Administration [SAMHSA], 2008; SAMHSA, 2013). Mental health problems such as depression, anxiety, and post-traumatic stress represent health disparities that are more prevalent among women, many of whom are of childbearing age (SAMHSA, 2013a; SAMHSA, 2013b). Women constituted 29.4 million of the ambulatory care visits with a primary mental health diagnoses between 2005 and 2008, as compared to the 18.5 million of the visits for men (SAMHSA, 2014). Analyzing mental health and substance use disorders in an aggregated manner is significant from the research, clinical and population health perspectives, evidenced by the Diagnostic and Statistical Manual (DSM-5) of Mental Disorders. Evidence indicating that individuals with mental disorders are more likely than individuals without mental health disorders to experience a substance use disorder (SAMHSA, 2016) coupled with the research finding that mental disorders, such as anxiety and depression, are the most prevalent mental disorders co-occurring with substance use disorders further support this grouping (Hser et al., 2015). Considering the co-occurrence of substance abuse and other mental health disorders, integrated systems of care treatment programs (SAMHSA, 2014), and the similarities of contextual risk factors that are parallel for both maternal substance use and mental health disorders, this dissertation study groups both conditions (i.e., substance-related disorders and other mental health disorders) together with respect to associated
risks and consequences and describes differences when applicable. Thus, this study
groups both conditions (substance use and other mental disorders) together.

Many social and health effects are associated with having a mental disorder,
including homelessness (Conners et al., 2003; Leonard et al., 2008), arrests (Conners-
Burrow et al., 2013), single parenthood, dependent and unstable housing (Hser et al.,
2013), violence (Conners-Burrow et al., 2013), unemployment (Dvir, 2012), stress (Jaser
et al., 2011), mental trauma related to physical and sexual abuse (Woodhouse, 1992), and
disrupted familial relationships and mothering capacity (Jaser et al., 2011; Perera, Short &
Fernbacher, 2014). The lives of women with substance abuse problems are
characterized by adverse circumstances such as homelessness and arrests (Leonard et al.,
2008; Binswanger et al., 2010), single parenthood, child neglect and abuse (Conners et
al., 2003); conflict, chaotic and poor living environments (Hogan et al., 1998), violence
(Perucci et al., 1991), and family problems (Arria et al., 2012).

Effect of Maternal MD on Children

Most often, women with MD are the sole caretakers of their children (Dvir, 2012).
In terms of the children, more than 1 million children in the United States live with their
mother who has a mental disorder (NSDUH, 2015). Mothers with MD have impaired
parenting practices (Arria et al., 2012; Perera et al., 2013), such as decreased parental
monitoring and supervision (Latendresse et al., 2008; Stanger et al., 2004); poor quality
parent-child interactions (Johnson, Cohen, Chen, Kasen, & Brook, 2006; Arria et al.,
2012); parent-child conflict (Arria et al., 2012); less parental warmth; and inconsistent
and harsh discipline (Stanger et al., 2004).
Maternal MD is linked to poor mental health and psychosocial functioning child outcomes (Hammen & Brennan, 2003; Jaser et al., 2011). Researchers of a prospective cohort study with a random sample of 396 children and their substance-abusing mothers found that 22% of the children had total scores on the Child Behavior Checklist (CBCL) (Achenbach, 1991) above the borderline (T-Scores, 65-69) or clinical cutoff (70 or above) (Hser et al., 2013) approximately 10 years after the mother’s admission to substance abuse treatment. Elevated scores were more common in the externalizing domain (disruptive behaviors, including rule-breaking and aggressive behavior) where 24% of the children had scores in the borderline/clinical range than in the internalizing domain, where 16% of the children scored at or above the borderline/clinical cutoff.

The effects of maternal MD on adolescents is of key concern. Adolescent development is crucial in establishing a healthy life trajectory, as experiences during adolescence shape the experiences and opportunities of later life (Zarrett & Eccles, 2006). Jaser et al. (2011) showed that adolescents of mothers with a history of depression used fewer primary control coping strategies, such as problem solving, emotional expression, and social support seeking (Jaser et al., 2011). Thus, such contextual risks associated with having a mother with a mental disorder, challenges the developmental trajectory of adolescents of mothers with MD.

*Strength-Based Approach for Research on Adolescents affected by Maternal MD*

While maternal MD may produce harmful trickledown health effects (SAMHSA, 2009) for mother and child, some children thrive and experience healthy development despite the challenges confronting them (Gelkopf & Jabotaro, 2013; Hser et al., 2014).
Risk-based and deficit-focused approaches constitute a majority of the existing literature regarding the effects on children of maternal MD and their families, despite recent evidence highlighting the significance of illuminating protective factors (CDC, 2015; Children’s Bureau, 2015). In spite of the multiple risk factors, adolescents of mothers with maternal MD can be resilient (Leonard et al., 2008; Criss et al., 2002), resistant to risky behaviors, and optimistic of a better future (Ronel & Levy-Cahana, 2011). Thus, examining resiliency – i.e., the characteristics or strategies, such as self-management, employed by adolescents of mothers with MD that helps them to persevere and succeed despite challenges is merited.

Theoretical Framework

The model guiding this study is the Individual and Family Self-Management Theory (Ryan & Sawin, 2008). Self-management processes occur in the context of risk and/or protective factors (Ryan & Sawin, 2009). Self-management is defined as the dynamic interaction between an individual’s knowledge and beliefs and behaviors that help them acquire and use skills to manage stable and/or complex, challenging moments. Behaviors such as goal setting, self-monitoring, emotional control, decision making, self-evaluation, and reflective thinking constitute self-management. The focus of self-management includes the interplay between individual, social, and environmental factors, including self-perceptions, positive social relationships, and self-regulatory skills and processes to manage normal and demanding conditions (Sawin et al., 2009).

Linkages between self-management, positive youth development, and health status (Modi et al., 2012) exist in the literature. There is an association between self-regulation, a process of self-management, and adolescent outcomes. For example,
Raffaelli & Crockett (2003) demonstrated a relationship between decreased levels of self-regulation and negative behavioral outcomes among at-risk adolescents. Hughes, Crowell, Uyeji, & Coan (2012) reported on an association between poor self-regulation and family conflict; other studies focused on the relationship between self-management and positive outcomes. For example, Moffitt et al. (2011) found linkages of self-management with healthy behaviors. Others have examined self-management processes among adults and children with chronic conditions using a condition-specific approach (Modi et al., 2012; and, Denison et al., 2015).

Despite processes that occur during self-management to help individuals during challenging times (Glantz, 1987), there is a lack of research investigating self-management among adolescents of mothers with maternal MD. Furthermore, few studies obtain the perspectives of adolescents of mothers with MD, who can offer valuable insight into their experiences. Gaining knowledge of how they manage their life circumstances, mother’s distress and parenting practices may lead to a better conceptual understanding to help inform intervention development. Furthermore, getting their opinions and allowing these adolescents to share their stories provides them with an opportunity to use their experiences to contribute to the development of protective-focused interventions.

**Purpose**

The purpose of this study was to explore, from the adolescents’ perspective, the individual-level self-management resources and strategies among adolescents whose mothers have MD. The Individual and Family Self-Management Theoretical Framework informed the following research questions:
1. What are the self-managing knowledge and beliefs among 10 to 19-year-old adolescents whose mothers have MD?

2. What are the self-management behaviors of 10 to 19-year-old adolescents whose mothers have MD?

Methods

Design

This study was ancillary to a randomized trial of a family-strengthening home health intervention, *Healthy Home*, for mothers receiving outpatient mental health, substance abuse, or case management services. Children ages 10-19 of mothers enrolled in the parent study were interviewed at the end of their mother’s participation in the parent study.

Qualitative research methods were employed to gain an understanding of the self-management resources of adolescents whose mothers have MD. To understand self-management experiences among these adolescents, the narrative approach was used, which is an approach chosen for its suitability in understanding a phenomenon not well-researched (Creswell, 2013). This approach allowed adolescents to express their lived experiences of self-management (Creswell, 2013). Face-to-face, semi-structured interviews were conducted using a script developed specifically for this study. As opposed to structured interviews, semi-structured interviews, a flexible interview approach, afford participants the opportunity to more freely express their perspectives in their choice of words (Cohen, 2006). The script included open ended questions (see Appendix A) to build rapport; the questions also addressed parenting practices, self-
management, and the ability to overcome adverse experiences and probes that prompted more detailed responses.

Participants and Setting

Inclusion/Exclusion Criteria. To be eligible for the parent study, women: (1) were enrolled in outpatient substance abuse/mental health treatment or case management, (2) had at least one minor child with whom they have at least monthly contact, (3) were age 18 years or above, (4) were capable of giving informed consent and comprehending either English or Spanish, and (5) were willing and able to participate fully in the protocol. To be eligible for this study, children were: (1) the biological, step, or adopted child of a mother enrolled in the parent study, (2) aged 10-19 years; (3) the signed permission of a legal guardian to enroll in the study (if under age 18 years old) was provided; (4) assent to participate in the study (or consent if age 18 years or above) was obtained; and, (5) English speaking and comprehension. Adolescents who did not speak English were excluded from the study.

Procedures

Recruitment and Screening. Approval by the University of Miami’s Institutional Review Board (IRB) was obtained prior to study recruitment and data collection. Participants were recruited through their mother’s participation in the parent study, a randomized clinical trial which compares “Healthy Home,” a nurse-led, home-based, family strengthening health care program for mothers receiving outpatient mental health treatment and/or case management services and their children. For the parent study,
mothers were recruited from community agencies that provide a wide array of mental health (including substance use) and case management services, some providing adult and children health services.

For this study, mothers with eligible adolescent children were identified by the interviewer, using the parent study’s demographic form; the interviewer explained the study and asked for the mothers’ permission to approach the adolescents regarding their participation in the qualitative study. Recruitment flyers were distributed to mothers and adolescents interested in participating. Given the mother’s preferred language was either English or Spanish, English and Spanish recruitment scripts were developed and IRB approved. The interviewer served on the parent study as the study coordinator and home-health nurse interventionist, thus had previous affiliations with four mothers of the adolescent sample while serving as a home-health nurse on the parent study; these affiliations were recorded on field notes and interview transcripts. Participants were compensated: those aged 10 to 12 years received a $10 gift card and those aged 13 to 19 years received a $20 gift card, which were the same differences in compensation of the parent study.

The number of children per mother ranged from one to three. This information is important in understanding household/family composition whose members could be instrumental in social facilitation processes involving the adolescent. Ages and racial/ethnic information of the adolescents is provided in Table 5. Fourteen adolescents were born in the US; the remaining, in Latin countries. Data saturation, the point during data collection and analysis at which no additional information was found from the interviews (Kerr, Nixon, & Wild, 2010), determined the sample size (Munhall, 2007).
Processes for establishing saturation included: thoroughly reviewing transcripts, and developing a codebook containing theory-informed predetermined codes, a table with theoretical concepts defined, and a table including each theme with corresponding categories, subcategories and participant quotes (Guest, Bunce, & Johnson, 2006; Kerr, Nixon, & Wild, 2010).

Interviews were conducted in private settings according to the family’s preference. Twelve (12) interviews were conducted in the mother’s home, 5 in the home of other family members and 2 in the agency where the parent study was being conducted. The same interviewer conducted all 19 interviews. Prior to starting the interviews, the following was reviewed with the participant: IRB approved standard of procedures and steps outlining the interview process, consents/assents to ensure signatures obtained, and information regarding confidentiality, voluntarily withdrawing, and/or taking a recess at any point. The adolescents were encouraged to speak freely during the interview. Promoting freedom of expression facilitates a balanced researcher-interviewer relationship that fosters disclosure, trust, and a comfortable environment (Orb, Eisenhauer, & Wynaden, 2001).

Interviews were conducted in English and recorded using a digital audio recorder. Interview times ranged from approximately 20 minutes to 1 hour. The interview questions were designed in consultation with the study mentors (whose expertise included but was not limited to qualitative research and/or human subjects’ protection).

One-time interview follow-up phone calls for member checking purposes were conducted with 12 participants between two to eight months after the interview was
conducted to ensure the adolescent’s core experiences were captured; the remaining seven participants were unreachable by phone despite multiple call attempts.

Analysis

Qualitative content analysis was employed to systematically classify the data and identify and describe central concepts and themes (Hsieh & Shannon, 2005). The directed content analysis approach employed allowed existing theory, the Individual and Family Self-Management Theory, to answer/address the research questions (Hsieh & Shannon, 2005).

Data analysis occurred after each interview; this approach continued throughout the study (Creswell, 2013). Ongoing analysis was instrumental for affording iterative processes and interactions with the data, and informing data saturation. The interviewer conducted the analysis in collaboration with a mentor, a PhD prepared Family Psychiatric Mental Health Nurse Practitioner (PMHNP-BC) and expert in qualitative research and research among at-risk adolescents. The Atlas/ti, a qualitative software that permits data reading and management (Creswell, 2013), served as a data organizer. For example, the software aided data management by reassembling large amount of text into one document, which allowed comprehensive data examination. Concurrent activities such as field notes and code documentation describing the subjects, settings, participants’ dialogue, events and activities, the participant’s and interviewer’s behavior, and reflections were conducted to enrich the analysis (Creswell, 2013). Specifically, a codebook was created and captured major concepts in the interviews.

Interviews were transcribed into the Atlas/ti software by three IRB-approved study personnel trained to use the software. The interviewer listened to each interview
recording while reading along the transcribed text for accuracy (MacLean, Meyer, & Estable, 2004) and to get acquainted with the interview details. These transcripts were analyzed using the “directed content analysis approach” (Hsieh & Shannon, 2005).

Directed content analysis permits the conceptual validation or extension of an existing theoretical framework or theory (Hsieh & Shannon, 2005), and was selected as a fitting study data analysis method. Directed content analysis is more structured than conventional approaches (e.g. coding categories originating straight from the data) since guided by more structured processes (e.g. predetermined categories) (Hsieh & Shannon, 2005). Directed content analysis permitted the theory to address the research questions and inform the results (Hsieh & Shannon, 2005); thus, concepts of the Individual and Family Self-Management Theory were identified as initial coding categories. Subsequently, operational definitions for the categories were determined based on the theory (Table 6). The goal of the research was to identify and categorize all accounts of self-management; thus, the steps of first reading the transcript and highlighting all text that, on first impression, seem to represent self-management and second, coding using the predetermined codes was a suitable method, increasing the study’s trustworthiness (Hsieh & Shannon, 2005). A table including categories, subcategories, quotations, and themes and another table showing data reduction were produced. The interviewer examined subcategories for patterns and relationships, which were reduced through merging subcategories with commonalities. Consensus on codes, categories, subcategories, themes, and the subthemes reflecting both manifest and latent content was reached with the PhD Committee member.
Enhancing Credibility

Data validation was pivotal in enhancing rigor and the trustworthiness of results (Bengtsson, 2015). To enhance credibility, detail related to the participants, interview settings/sites, and themes were provided, and consensus of codes, categories, subcategories, themes, and subthemes were sought among the interviewer (a doctoral student) and PhD prepared study team member (Creswell, 2013). To optimize validity, procedures involved multiple levels of analysis, exploring narrowed codes to broader themes and subthemes, thoroughly scrutinizing transcripts, and member checking (Harper & Cole, 2012) to validate the accuracy of accounts (Creswell, 2013). Accurate inferences drawn and presentation of participants’ realities were extremely paramount; thus, validity of findings was established during follow-up calls in which participants were asked if the interpretations truly reveal the core of their experiences (Parse, 2001).

Findings

Three themes and seven subthemes depicting various dimensions of the adolescent’s self-management resources emerged in the analysis (see Figure 4). The three themes comprised: (1) the construction of healthy, positive self-concepts - self-management knowledge and beliefs; (2) resolving demands – engaging in various forms of self-regulation during normal and challenging situations; and (3) balanced socialization – the interplay between individualism and meaningful social connections. Direct quotes from participants are shown in italic.

Theme 1: The Construction of Healthy, Positive Self-Concepts - Self-Management Knowledge and Beliefs

This theme, which aligns with research question 1 (What are the adolescents’ self-management knowledge and beliefs?) manifests participants’ self-perceptions regarding
confidence in their abilities to manage themselves and intentionally influence their functioning and course of environmental events. Adolescents were asked “Tell me some things about yourself”, “What are some things that you are...good at,” and “Would you say that no matter what happens, you can get something good from it.” Adolescents were also asked questions related to their belief that employing a behavior will yield desired outcomes including: “Tell me about a time when something bad happened, but you were able to make it positive” and “Tell me about a time you had to handle something bad that happened.” Posing the questions in this manner helped to determine the adolescent’s knowledge and beliefs related to self-management during challenging situations. To understand the adolescent’s knowledge and beliefs regarding the ability to reconcile the confusion and anxiety resulting from conflicting, competing demands, the participants were asked: “How did you learn the skills to do something good/be positive when bad things happen” and “What are some things that help you when you are stressed or upset.” Additionally, adolescents were asked about their ability to resolve distress resulting from challenging demands with the following: “Would you say that no matter what happens, you can get something good from it?” More specifically, particular attention was given to the adolescent’s self-perception of abilities versus others’ perception about the adolescent’s abilities. Two subthemes emerged: (a) self-efficacy (including goal setting), and (b) the capacity to control the outcomes of life’s events, including choosing the good view, positive thinking.

Subtheme a, Self-efficacy (“I just be confident.”). Adolescents expressed positive self-concepts, including their strengths and talents. One expressed wanting to “stand out for all the good things.” Most adolescents ($n=18$) expressed good academic
functioning/competences. All adolescents expressed one or more of the following talents/assets: drawing/painting, sports, dancing, cooking, organizational skills, learning, and helping others. For example, a 14-year-old male expressed, “at the end of 5th grade I started doing good…my teachers… gave me a medal for the being the [sic] most improved kid…cause I…started doing good…I learned being positive makes you…get a good life, … pass the grade, and… a smart kid.”

Adolescents provided descriptions of their confidence in effectively engaging in self-management, during normal life or in stressful situations. Adolescents spoke about their self-motivating capacity. For example, one 19-year-old male stated, “I mean I’m a self-motivating person, like I really don’t depend on others for motivation.” An 11-year-old male expressed, “Yea, like when I’m seeing like I’m doing low or…not giving my best, I’ll be like ‘oh like I need to now step up and make sure that I’m getting everything done’.” Another example of self-efficacy among the adolescents was a 12-year-old female who, when asked about how she felt about her artwork accomplishment being displayed at the school, communicated, “That make me feel good because I already know…I could do anything I want if I put my mind to it. It’s just the way that I am.”

Some adolescents described their confidence as deeply embedded within themselves. For example, when describing confidence, a 12-year-old adolescent expressed, “I think that it comes from inside of you.” Another example was a 19-year-old male who reported, “It’s just the type of person I am.” Adolescents expressed confidence in their ability to achieve regardless of others’ perceptions of their abilities. A 16-year-old female expressed, “I mean if I put my mind to it you know, just because I don't have like a nurturing teacher doesn't mean I’m not going to succeed by myself.”
Subtheme b. The Capacity to Control the Outcomes of Life’s Events – Choosing the Good View, Positive Thinking (“When I’m seeing like I’m doing low, I’ll be like ‘oh like I need to now step up.’”). This subtheme enunciates the idea of managing life challenges. Adolescents spoke easily about a sense of agency, the ability to influence their functioning and course of environmental events, for example, “I’m the type of person that I like having control over my life.” One 11-year-old male, who was faced with a situation in which he had to improve his academic functioning, stated, “Yea, like when I’m seeing like I’m doing low or like I’m not giving my best, I’ll be like ‘oh like I need to now step up and make sure that I’m getting everything done’.” Expressions relating to confidence in their ability to engage in a behavior under stressful situations was common. For instance, all adolescents expressed their ability to resolve problems. A 14-year-old male stated, “I like trying my best at things even though that it’s hard cause like other people would say no I don’t want to do it, I can’t do it but then I, I would at least…try to do it.”

There was evidence to support the adolescent’s internal locus of control, belief that the adolescent is responsible and in control over their life experiences and outcomes. For example, when describing an academic challenge, one 14-year-old male stated, “Even if they [teachers] don’t show you, you can do it. It looks hard, so you think about it, you work it out and then it comes, it’s like easier.”

Intersecting with this theme included adolescents choosing the good view which entailed optimistic and positive thinking. Adolescents expressed optimistic beliefs including the ability to reframe negative situations with directed, positive thinking. For example, a 13-year-old female expressed, “There’s always a view so you always look at
adolescents spoke about choosing the good (e.g., options, attitudes) over the bad to achieve a positive outcome. The only 19-year-old male who reported a history of sexual assault and post-traumatic stress disorder expressed:

Participant: Because I’ve seen a lot and I know more than the, probably what the normal person does, like I know that there’s 2 sides to the world. There’s a dark side and there’s a good side. Like most people try to pretend like the bad side doesn’t exist [mhm]. I lived in the bad side so I know all the things that there really is out there in the world.

Interviewer: So, what side would you say you're living in now for the most part?

Participant: Oh, the good side! Like I do a lot of good things now, I try.

This same 19-year-old, when describing a situation that warranted him disassociating with negative peer influences, looked at losing peers in a positive light. He stated, “when I lost all my friends. I probably looked at it instead of a negative way, I… looked at it as something positive like I was getting fake people out of my life. I didn’t see it as something bad, I saw it as something positive.”

Theme 2: Resolving Demands-Engaging in Various Forms of Self-Regulation during Normal and Challenging Situations

This theme is aligned with research question 2 (What are the self-management behaviors of the adolescents?). Beyond holding self-management knowledge and beliefs (Theme 1), adolescents engaged in various forms of self-regulatory processes to positively adapt and respond to normal and adverse situations. Two subthemes emerged: (a) use of internal resources – self, situational, and environmental appraisal (e.g., directing their
focus, self-containment, and emotional control), and (b) use of external resources (e.g. symptom management, medication adherence, and outlets of stress).

Subtheme a, Use of Internal Resources - Self, Situational, and Environmental, Appraisal (e.g. directing their focus, self-containment, and emotional control) (“I’ll try to like keep my distance away cause I don’t want to get in trouble.”) included ideas of self-monitoring, reflective thinking, and self-evaluation. Adolescents reported self, environmental, and situational appraisal, cognitive responses when confronted with a situation within their environment, including risk recognition and information processing. For example, a 12-year-old expressed, “I didn't wind myself up in that because I just walked away cause I was like…them sitting their fighting not going to get me nowhere so why should I sit there and be worried.” For example, a 15-year-old female with a history of conduct problems reported, “I was passing by a rough time and stuff and at the time I didn’t have that much of a good friends so…the people that were suppose to be my friends they told me to start doing like these things that weren’t good.”

Most adolescents reported self-improvement strategies in decision making \((n=15)\). A 12-year-old female expressed, “cause I didn’t want nothing else to happen like it happened in 5th grade, I wanted to like improve myself. I wanted to be better that where I was.” All but one adolescent expressed choosing better avenues and aligning themselves with the good through decisions made. For example, a 12-year-old male expressed, “cause I saw how the change of how the good people was acting and how the bad people was acting and that led me to go out and be a good person.” Sixteen of the nineteen adolescents provided descriptions related to understanding consequences that influenced their decisions made. For instance, a 14-year-old male expressed, “Well,
uh…like I thought to myself like if I stayed with the kids that made me um play around
too much I wouldn’t pass the grade so if I left them I would pass the grade.”

Self-evaluation was described in terms of learning from mistakes and futuristic
thinking, particularly among those adolescents who described a history of risky
behaviors. For example, a 16-year-old female expressed, “Yea um I mean you just learn
to, you just learn from your mistakes don’t do it again, learn to handle a problem without
going over your head and just blare out what you think is the right thing to do.” An 11-
year-old expressed, “I’ll just make sure that I finish it and not like interrupt cause then I
would think of the future and like…if I don’t pass then it’ll be my fault of letting
anything like that happen and then I’ll notice that if I’m unfocused then I’ll like stop a
little bit think about it and then keep on going.”

Intersecting with this subtheme was the adolescent’s expressions related to
management of response (“I just act like there’s nothing surrounding me and I just kept it
moving.”) through directing their focus (mindfulness practices), self-containment, and
emotional control. The expression – (“I had to learn how to compose myself”) echoes the
adolescent’s cognitive flexibilities to control their reactions in response to unexpected,
demanding situations. Thirteen of the nineteen adolescents described their experiences of
self-containment. One adolescent described a challenging situation in which she had to
assist her grandfather whom she loved dearly during a moment of sickness while
containing herself. The 14-year-old female expressed, “I was like ok, but um, I was
getting better like I was like trying to contain myself and I was like ok you’re good.”

Adolescents engaged in positive, self-developing activities to manage (e.g.
balancing recreation with responsibility and/or sleeping as a self-management enhancer).
One of the 14-year-old males said, “Well, I would like to skate board sometimes [aw] and
go out and run or, I would like to go to my cousin’s house and go to the gym or
sometimes read or watch TV, or help my mom with something.”

When describing directing her focus, one of the 15-year-old females expressed,

Well, because instead of focusing on the bad things that got me angry and stuff, I
focus on trying to do the drawing good and focus on how the lines have to be and
how the details of the drawing have to be, so I focus mainly on the drawing and
not on what got me mad and like that kind of makes me like more relieved and
like make me forget about the anger.

Subtheme b, Use of External Resources (e.g. symptom management, medication
adherence, and outlets of stress) (“I’ll discover all the contextual that I could find”) enunciates
the idea of adolescents mobilizing and activating internal and external
resources to achieve wellbeing through planning and action processes. A strategy
expressed by most adolescents was help-seeking behaviors including enlisting and
speaking up for support (n=14). For example, when discussing seeking peer support to
manage competing demands of dealing with the loss of her grandfather, a support person,
and avoiding academic failure, the 14 year female stated, “… when my grandpa first
passed away it was kind of crazy here like you know… everybody was sad and like I was
sad too but I like I had to like pass the grade cause I was halfway into the grade and I had
to pass it, so I had to … like keep my mind off of it and just keep going with school cause
I wasn’t going to pass…so I would ask my friend for help and she’d teach me this and I’d
learn you know. I had to learn how to compose myself to pass the year you know, cause
I didn’t want to repeat that year you know.”

It is worth mentioning that a subset discussed using recommended psychotropic
medication and talk therapy to “like balance everything out.” Seven of the nineteen
adolescents described using recommended pharmacological therapies which some
described beneficial effects of medication adherence \((n=3)\). A 14-year-old male
expressed,

> Ok, without the medication, I’ll play like games…like a fighting game then I
would play a football game, then when I was doing good [taking his medicines] I
would do like Iready [a learning program], reading plus… some other website
…and that have to do with school work.

All adolescents recognized the purpose of their medications. All males in the subset of
adolescents using medication expressed a need for a balance between the medication
helping and them helping themselves. A 14-year-old male expressed,

> Cause every time I take the medicine it just makes me feel like I’m being
controlled by pills so I don’t want to like, I want to do it for myself. I don’t want
to drink a pill to do it…Like it will help me out but I still want to do it by myself
so I could learn how to like [sic] not get angry all the time.

A 12-year-old male expressed, “I think it’s also my medicine and then even if I don’t take
it like I know what I should do... and I still do good things.” When asked how the
medication helps, a 15-year-old female expressed, “Um, they just kind of like balance
everything out.” This adolescent linked the medication with an improved sense of who
she was. When describing the impact of medication on improved functioning, a 12-year-
old male expressed, “And my teachers had started to see me as a good person and how
I’m suppose to be.” This adolescent went on to express, “It made me feel good cause then
I started doing my work correctly then I started doing great behavior and then they started
giving stuff to me for good behavior.”

Among those currently receiving or with histories of mental health treatment, two
female adolescents, expressed benefits of collaborating with the provider. A 14-year-old
expressed, “…the therapist made me realize that it was better to come and talk about my
problems.” When describing how a collaboration with the mental health provider bridged health literacy gaps in the adolescent and the adolescent’s mother’s health knowledge regarding the adolescent’s mental diagnosis, a 15-year-old expressed, “Well um, it… explained to me what was ADHD and everything and when they explained to me what it was, I was like now I know why like I was never like able to like concentrate in class and everything….”

Intersecting with this subtheme was self-reliance in response to ineffective outside resources. Two adolescent females and one adolescent male described ineffective collaborations with mental health providers and how they resorted to utilizing internal self-management resources to help them manage. A 15-year-old female described how she felt “like the therapist wasn’t too much help” and thus engaged in self-help strategies which included learning to “actually like” and “love” herself.

A 19-year-old male who was “positive for ADHD” expressed,

I mean to be honest I’ve always hated to go into the doctor to like to all those treatments… I’ve had a therapist, a case worker, a psychiatrist, a probation officer. I’ve had all of those things and like every time I go to speak with them like I just feel that I was another case with them, like I never really felt like they actually cared about what I was saying, they were just like ‘oh whatever’… and then the other thing is they were just like getting paid to be there with me …that’s the way I would always see it…like I just …didn’t like the experience I had talking with them…because I felt like I didn’t matter. I just felt like I was another patient…I never really felt like people were being real with me [mhm]. I felt like they were just…trying to…kill time.

This same adolescent defined psychology as an “area where like you just want to help people.” He further provided additional insight on ineffective mental health services by describing, “I feel like most of the psychiatrists…just look at it as that’s their job, they didn’t look at it as the real fundamental of it, like that it’s to like help people be a better
person.” He then expressed, “cause I feel like if more people saw it as that instead of as a job probably the results that they have with people would be probably much different.” There was strong evidence to support the adolescent’s ability to help themselves while resolving competing demands through resorting to internal mechanisms. For example, when asked who taught the adolescent a skill, the only 15-year-old male expressed, “Um, I’m teaching myself.” One adolescent described leaving a setting of discord to better function; the only 13-year-old female stated, “When my grandma was moving to Virginia um the whole house was turned upside down and I use to have to do work…so I use to just keep going to school and doing my homework wherever I could.”

These examples provide evidence of adolescents navigating their resources and balancing internal and external resource utilization. These adolescents find their help to manage themselves, whether within or externally. Symptom management included emotional and behavioral self-regulatory processes to manage stress-provoking moments: “If I’m … really stressed out, I … like to be alone and … listen to music.” When describing symptom management, adolescents spoke about moments of solitude for rejuvenation as a means of escaping the problem source ($n=7$), internal and external resource utilization ($n=17$), positive thinking ($n=14$), and/or engagement in positive activities/treatment regimens to yield healthy outcomes ($n=19$). For instance, a 15-year-old female stated, “I hear music or … try to like to find a spot around the house that's like quiet so I can like concentrate on my work and not get that much stressful.”

Adolescents described positive coping strategies and adaptational processes. Some examples of stress-inducing situations expressed by the adolescents they worked through to maintain stability related to family’s low-income situation or transportation
loss, academic challenges, home discord, mother’s adverse situation, a relative’s illness, family separation, parent’s divorce, and dangerous environments. When discussing how she deals with stress, one 12-year-old female said, “I’ve always think positive and no matter what the situation is I’ve always thoughted positive even though you see me like there and like stressed out …, I always gonna have that smile on my face or that positive thing.”

Through choosing and engaging in positive activities such as sports (e.g. basketball), sleep, recreational activities (e.g. artistic manifestation, writing, and music) and spending time with significant others (e.g. family and peers), the adolescents were able to be distracted from the problem and “feel better.” When discussing avenues for channeling stress, a 15-year-old female expressed “I like sometimes write poetry or something and release my stress.” She adds, “when I get mad … I plug in my earphones and like put my [sic] music … and like… throw away the whole world … to like just calm down.” Additional stress reducing activities beyond “getting away from everyone” include self-talk and self-instruction. For example, when an adolescent was asked what helps during a stressful situation, the 13-year-old female expressed, “find a little corner and talk to myself.”

Theme 3. Balanced Socialization-The Interplay between Individualism and Meaningful Social Connections

This theme manifests facilitation processes in the context of social relationships that enhance the adolescents’ development and capacity to change. Three subthemes surfaced: (a) family, peers, teachers, and providers as self-management enhancers, (b) mothers as cultivators – positive parenting practices, and (c) participation as a member in social structures – making a contribution and the power of expression (disclosure).
Subtheme a, Family, Peers, Teachers, and Providers as Self-Management Enhancers ("I need some kind of support system"). Adolescents mentioned the support from peers and members of the adult world as self-management resources. This theme echoes family and peers as a stronghold and social, ecological, environmental aspects that facilitate self-management. Adolescents identified peers and members of their adult world (e.g. family, teachers, and/or providers) as social facilitators and enablers, and felt that their actual or implied presence in their lives promoted their positive functioning, coping, and development. When describing the impact of the teacher in facilitating their learning, a 12-year-old female expressed,

Yea cause… the teachers … would explain to you things that like if I dont understand something I … ask her she would explain to me and … show me … what I don’t understand. I would ask, she would ask me and I’d tell her …the thing that I dont understand, she would explain to me really good.

The aspects of their social resources adolescents valued significantly related to social networks representing a breeding ground for positive learned behaviors, trusting relationships, opportunities to confide in others, and having someone to count on. For example, after identifying his family as a significant support system, while expressing what made his family important in his life, an 11-year-old male voiced, “they [referring to family] all teach me…things to do and… make me try new things... it’s very important for me to have them that way like in any problem that I have in the future I know how to take care of them by them.”

Adolescents spoke a great deal about the family as a field of simultaneous, positive energies. For example, when describing an appreciation for her family’s role
during a challenging situation, a 15-year-old female expressed,

Um, well the fact I guess that like at the time I felt like nobody actually cared for me and like there wasn’t nobody that actually loved me and stuff, but when that happened um there was actually a lot of people [about the family] there and even my father was there which he was pretty much never with me at the times and everything and like everybody was there at the time that like I was like not good and stuff so like I noticed that…I actually have people that cared for me and stuff so I’m guessing the fact that there’s actually people like that looked up to me and cared about me and made me like be more strong [ok] and like not do that again.

When describing his appreciation for the family unit, a 14-year-old male expressed, “That they love me and I love them and they like teach me good things and they never mistreat me.” Fifteen of the nineteen adolescents expressed family togetherness. A 12-year-old female stated, “It feels really really good because you get to…have time with your family and not be… like alone and its good having together with family.” One 12-year-old female repetitively verbalized the word ‘together’, “Um we live together and we're always like together. Like… we always have like every time we're together and we were either eating together or watching a movie together like everything is together.” A 12-year-old female expressed, “Yea, I feel like… I need to be with my family together because it’s just a part of me. I like being together with my family.”

Some adolescents described collective efficacy, the belief in their family addressing shared problems and pulling together during adverse situations. An 11-year-old expressed, “They all teach me like little things to do and like they’ll just like make me try new things…it’s very important for me to have them that way like in any problem that I have in the future I know how to take care of them by them.” When describing the loss of a loved one who was a father figure, a 14-year-old female expressed, “Everyone started being like oh you’re doing better and how are you doing it mom and I’ll ask her and she’s like little by little we would get better.”
When describing the social influence of peers, a 14-year-old male expressed, “Yeah they’re a good influence. They’re not bad. They’re a good influence [ok]. They help me out and everything if I need help. In school wise they go and help me out if I need help. In house wise or anything they go and they help me and stuff like that [mhm]…so that yea we’re a good influence and stuff like that.” When describing the impact of teachers, a 16-year-old female expressed, “Umm most of them want students to succeed…like if they don't understand the work then they [teachers] take the time to help.”

All adolescents reported the support they receive from peers, family, providers, and/or teachers as instrumental to enhance their development or manage a challenging moment. For example, when describing the need for support in the context of a lack of paternal support, a 16-year-old female expressed, “Because my dad's not, so I need some kind of support system.” While all described persons in their ecological world to be instrumental for engaging in healthy, positive behaviors, many ($n=14$) described the importance for a balance between being enabled and being the facilitator/enabler themselves (self-enablement). Some described the need for managing time amongst members in their social structures. A 14-year old male expressed, “…I spend more time with my family than my friends cause you know family's first…I spend more time with family and then I’ll make room for my friends and I’ll go to their house and hang out and sometimes I’ll stay over their houses a few days.” When describing the importance of peers, one 14-year-old female stated,

They know what’s important to me and like I know what’s important to them and we'll like support each other and we could just tell each other like whatever crap we want and we won’t like judge or like give lectures or like um reprimand. Like…we'll carry each other to the point, we'll care about each other to the point
where like if you’re doing something bad like I would tell you like that’s bad and you shouldn’t be doing that but it’s not like I’m going to get you in trouble for doing that, it’s like I’ll help you because I want to help you.

Twelve of the nineteen adolescents reported a sense of belongingness when describing social facilitation. While describing previous maladaptive behavior, a 14-year-old female expressed, “Because like…I don’t want to feel that lonely like I use to before because I use to feel that my mom and my dad were never there so like that's why I got into that stuff.” This adolescent expressed later in the interview that she felt her mother was more involved in her life at the time; she seemed to appreciate this maternal support. A 14-year-old female, expressed, “I don’t like being in a place where it’s like nobody wants me to be there.” Another adolescent stated, “We all need like to have somebody in our lives who could give us guidance so we wouldn’t do stupid things.” Adolescents expressed trust as an impetus for meaningful social connections. For instance, when describing confiding in others this 14-year-old female expressed, “I would tell her because I trusted her the most.”

There was strong evidence to support the importance for the support to be balanced, “with limits,” leaving space for the adolescent to contribute. For example, some spoke about members of the adult world being overprotective. One adolescent expressed, “I mean it’s [social support] important but at the same time I feel like I need my space at the same time you get me so like everything with limits.”

Subtheme b, Mothers as Cultivators - Positive Parenting Practices (“I mean cause she’s your mother, your main support system.”) reflects the idea of the mother’s critical
role as a self-management enhancer. Adolescents described their mother’s maternal parenting practices, including moments spent and communication with their mother. A 19-year-old male delicately sighed and was observed by the interviewer smiling when he expressed a moment with his mother, indicating there were many moments spent with the mother. His response was, “That’s a lot of times though, go fishing.” Another example is:

It’s fun and exciting cause then we can just go places that we never been before but my mom she would take us to the places that she been when she was a little girl then she would tell us about it so then it could be like generations and generations (12-year-old male).

While speaking of moments with their mothers, most expressed communication with their mother and confiding in her \(n=16\). A 15-year-old female expressed,

Well, she ask us like how my day was and um…she usually just ask how my day was and sometimes like from that starts going to another conversation about this other thing in school about the work. Sometimes she ends up telling me about something that happened in her work, this crazy thing that a driver did and stuff and like and it starts from one conversation and jumps to another one and stuff. Like sometimes we just keep on talking and stuff and like sometimes she falls to sleep so (laughs), I just start doing my homework again.

All adolescents spoke a great deal about the importance of maternal involvement and included adjectives in their descriptions about the importance of maternal involvement in their lives. A 14-year-old female expressed, “…she’s [about her mother] like one of the main support systems that you could have, like she always tell me that like um oh ‘no one’s gonna, no else is going to love you more than I love you, or like be there for you and like yeah.” Other examples are:

It’s important because if you didn’t have a mother that was in your life then you would be sad because if your dad was not a good person which my dad is but if he wasn’t…you would feel like you want to run away from home or you would um want to do something bad or not do good in school but if you did it would make
you feel happy, feel like you want to go do good in school...help her do chores
and help her if you have a sibling or not (14-year-old male).

Eight of the nineteen adolescents described the mother’s showing of affection
toward them. For example, a 15-year-old adolescent expressed, “She proves, she hugs
me, [sic], she kiss me, and she say good job.” Some described maternal support as
positive reinforcement. A 12-year-old expressed, “When um I had like a test that I got a
good grade on it, I told my mom and she’s like, she was like really proud of me cause I
get a good grade, or when like report cards came out I had like straight As and Bs.”

While describing appreciation for maternal support, few expressed the need for it
to be with limits. A 19-year-old male expressed, “I mean it’s important but at the same
time I feel like I need my space at the same time you get me so like everything with
limits [hmhm], the way I see it.” A 14-year-old female, expressed,

Like she wants me to be a part of everything cause sometimes I’m just like I don’t
want to do anything or like ... she’ll be like ‘oh you want to go out’ and I’m just
like o no I’m not in the mood and she would be like very like sad, and she’ll be
like ‘oh come on it'll be fun’ and um just like, ‘oh no I just wanna like go home’.
Like she always want to do, try and do stuff with me. Sometimes, um just like
‘oh I don’t know.

This expression of limits could allude to the adolescents’ movement toward
independence, which the mother may not be understanding.

Overall, the adolescents recognized the mother as “the main support system.”
Some adolescents distinguished the particular significance of the impact of mother’s
involvement. When discussing self-disclosure, a 12-year-old female voiced, “I think...
it’s best to tell your mom because your mom would always be there for you and I don’t
think you can trust a friend even though she's your best friend or whatever I don’t think
you can trust her because sometimes you know they could just blurt out the things that
you said and you could not trust them a lot.” Adolescents described the mother as a source of learned behaviors, counsel, and guidance. For example, one adolescent stated “cause without her [mother] I couldn’t do half of the things I do now.”

Among adolescents with histories of mental problems, maternal involvement served as a protective factor. A 14-year-old female expressed, “Now, I feel like my mom is in my life even more, she’s over more protective…and I feel…it's more important because like that I won’t fall and stuff again.” When describing how things may be without maternal involvement, a 12-year-old female voiced, “Because…it would probably feel like if um she wasn’t there…why would I even do this if I don’t even have her, but she she’s always been there for me, but it would feel like that I think.”

These examples provide strong evidence to support the significance and powerful influence of mothers’ involvement in the adolescents’ everyday lives, presence, availability, and responsiveness to their needs and its influence on the adolescents’ positive, healthy development and self-management. There was strong evidence of the developmental transitions that occur during adolescence, specific to changes and influences of meaningful relationships with those in their social structure.

Subtheme c – Participation as a Member in Social Structures-Making a Contribution and the Power of Expression (e.g. moments of speaking up) (“I want to serve”) incorporated service to others, and reciprocity. With respect to service, a 15-year-old female expressed, “I know some sick kids around and everything and I know that they are like some kids really hungry right now and I could just be that person to like help them out.” A 14-year old male stated, “And the reason I want to be inside the army, well I just I want to serve the country.” A 12-year-old female reported, “Well, it’s a lot
of people who could be doing something bad so I think I should just like help them out, not just myself or my family. I should help other people out cause if they need, if they don’t want the help I’m still gon give them that help.”

Adolescents recognized proximal and distal goals. Eighteen of the nineteen adolescent participants expressed an understanding of the importance of goals. For example, a 14-year-old female stated, “I have more of a goal for the actual like adulthood life like doing things and becoming somebody cause like I don’t want to like… I have this thing where I don’t want to like pass away and not make anything of my life you know.” A 14-year-old male expressed, “I want to work and really I just don’t want to be like a failure like those kids who got failed and got kicked out and they’ve been living on the streets on their own [ok] and their families couldn’t keep them so they…put their kids in orphanage and that’s pretty sad.”

Adolescents also described making amends for harm they had caused. A 19-year-old adolescent male reported, “Like as long as they feel proud about of who their son is [referring to himself here], like I feel that’s what matters cause I feel like…they had to suffer. I put them to suffer a lot over the years and like the least I can do is you know pay them back by being good, the least I can do for all the things they’ve done for me.”

Adolescents described participating in negotiated collaboration amongst those in their ecological systems (e.g. family, peers, teachers, providers (health, criminal justice) for various situations (e.g. improved academic functioning, suggestions for improvement, help during a hardship). Participants reported joint decision making as facilitating their self-management. An 11-year-old male expressed,

… Like my friends, my 2 friends got into a fight with each other and like…I was
like kind of sad and then I...brought them back like to become friends and we solved the problem together.

When describing a collaboration amongst herself, her mother, and a criminal justice worker, a 14-year-old female communicated a situation when an individual who physically assaulted her was put “on probation” as result of her mother collaborating with police officials.

A 13-year-old female stated:

Or there was um, well last year I think… in 4th grade…she [referring to mother here] went to go talk to the teachers and everything [mhm] and they’re like if you don’t bring your grade up you’re going to repeat the year, so I had to work harder and stay home for a whole week [mhm] putting up my grade.

A balance between being the enabler and being enabled by giving back treatment given to them including helping those who helped them was expressed by all adolescents. Accommodating their mothers through helping them during challenging moments was discussed. For example, a 14-year-old female expressed, “I know it’s hard for my mom cause she gets like…no family support. Like if she needs help with my brother, I’d be the one to like do it.” A 14-year-old male voiced, “I just…try to smile a lot and try not to like worry about anything bad [mhm] and try to think of everything that’s positive to like help her go through everything.” Helping additional members of the adult world beyond their mothers was an important aspect in them enabling others. A 14-year-old male described, “…I help out the teachers. I do it cause I feel like doing it for them so…they could really think that I’m like a real good kid that I like to help out.” A 14-year-old female spoke about her future evolving around service to a relative who cared for her.

She expressed,

Like when I can work, umma start working and...get a lot of money cause my grandma has been like taking care of all of us for so long...I want to get enough
money and become good enough that she [about her grandmother] can live with me and I could just take care of her.

There was evidence to support the adolescents as the change agent, actively engaging in reciprocal processes to produce change which involved mutuality; not only the recipient of resources but being a resource to others including members in the adult world (their moms, teachers, and other relatives) and peers.

Intersecting with this subtheme was moments of speaking up – the Power of Expression (“I like broke out and...I finally told somebody.”). This reflects the balance between being heard and speaking.

When describing an appreciation for the communication process with a significant person of the adult word, one adolescent expressed “she’ll sit there and listen and...then she’ll tell me what not to do and to do.” When responding to what makes the adolescent want to talk to her mother when distressed, the 12-year-old female stated, “I feel that I have to talk to the person and express myself.” When describing meaningful connections with peers, a 12-year-old female described it as a metaphor of juggling acts of speaking and listening: “they all listen to me and I listen to them.”

Many adolescents expressed moments of speaking up so that their voices were heard. When describing a challenging situation that involved a case with the Department of Children and Families where the adolescent’s relative was reported to the authorities due to a provider misunderstanding, a 14-year-old expressed, “Like, I had to come and I had to calm down and sit with the guy and I had to explain to him and he’s like no...umma close the case because...I see that you wanted to let go stuff with somebody and the lady understood wrong I guess.”
Adolescents expressed a benefit or feeling of relief with self-disclosure. The issue of disclosure is typified by the quote, “like I let myself go with that lady [DCF worker]…I wanted somebody to talk to.” Another example, a 14-year-old stated, “like she [mother] didn’t know about my problems…and I ended up telling her.” But others expressed critical situations where communication was inhibited. For example, a 19-year-old male who was sexually abused spoke about how after the abuse happened a police investigation was not proceeded since he “left a wall up” (did not speak up enough) but years later is when he “like broke out and…finally told somebody.”

Fourteen adolescents described the importance of their voices being heard. Examples are:

I remember and I sat down and like I let myself go with that lady [mhm]…and the lady instead of understanding...they had called DCF and they had opened a case and my mom and it was for my grandma and I didn’t want to open the DCF case on my grandma because she’s not the one supposedly cares for us [mhm] but like I wanted somebody to talk to (14-year-old female).

I’ll talk to my grandma…cause…she’ll sit there and listen and she’ll tell and she’ll understand and then she’ll tell me what not to do and to do (12-year-old female).

Well, in my mom hasn't really gone to school and resolved any of the problems because like she hasn’t had time and stuff but like when she hasn't been able…to …communicate with the teachers… she usually tells me to talk to them personally and like after that, sometimes the teachers say oh I'll give you extra credit because it was probably my fault, I probably misplaced the paper something and stuff like that (15-year-old female).

Although uncommon, it’s noteworthy very few adolescents expressed instances of barriers of self-disclosure. These included: when mother was stressed (“cause I see she got more problems every time”) and about sex, a “weird” topic.

There was evidence to support adolescents speaking up during moments of calamity/in response to conflicting situations, after prompted to do so, as proactive measures, and for advice/guidance.
Discussion

The purpose of this study was to gain an understanding of the adolescent’s self-management resources that may help to reduce the negative effects from living with a mother with a mental disorder. The challenges these adolescents expressed is congruent with the existing literature that clearly establishes risks confronting these adolescents. However, limited research explores multiple facets of self-management resources contextualized to these adolescents. Thus, exploring self-management, an understudied, significant, protective-focused area pivotal to the lives of adolescents with a mother with a mental disorder, is critical. Moreover, self-management equips these adolescents with resources to enhance their resiliency, adaptation and healthy functioning despite adverse situations.

The study’s descriptions expand the existing literature by contributing the lived experiences of various self-management resources of adolescents of mothers with MD. The various aspects of self-management explored (e.g. self-management knowledge and beliefs and behaviors) provide a broader scope of exploration than previous research (Murphy et al., 2009). Specifically, self-management knowledge and beliefs and behaviors, including self-regulatory processes during normal and stressful situations, and self-management enhancing social resources at the peer and adult world levels were explored. Risks confronting these adolescents are well-documented and include mental problems and poor social functioning (Chatterji & Markowitz, 2001; Hammen & Brennan, 2003; Hser et al., 2014; Jaser et al., 2011; Leonard et al., 2008). Furthermore, researchers that examine protective factors among at-risk adolescents predominately
focus on adolescents who perform better when in the presence of others (e.g. family) and conduct research, predominately, quantitative methodologically driven.

The findings from this study suggest that adolescents not only have the capacity to self-manage through their knowledge and beliefs and self-regulation skills and abilities, but they also employ self-management behaviors and social facilitation to manage themselves during normal and adversarial circumstances. The central themes that emerged from the interviews were: (1) the construction of healthy, positive self-concepts - self-management knowledge and beliefs, (2) resolving demands – engaging in various forms of self-regulation during normal and challenging situations; and (3) balanced socialization – the interplay between individualism and meaningful social connections that contribute rich, collective description of the contextual, individual level self-management resources of adolescents of mothers with MD. Too little research has explored this area in using this synthesized, multi-faceted approach.

The study’s findings about salience of family resourcefulness and parental involvement is congruent with quantitative methodological research that examined protective family factors among adolescents in the context of a maternal chronic illness (Murphy et al., 2009). The adolescents’ self-regulation abilities, social facilitation processes, behaviors, and reciprocal processes were interconnected, thus congruent with the Individual and Family Self-Management Theory (Modi et al., 2012). Despite the wide age range, there was not a significant amount of variation in the perspectives of self-management resources expressed overall; for the most part, the adolescents were able to conceptualize their lived experiences of self-management. Understanding the developmental influence on self-management in the context of maternal MD needs
further exploration. Although these adolescents are capable of managing, nurses, family, and the community are key supports in considering their developmental milestones/capabilities when facilitating adolescent understanding of the linkage between self-management and improved outcomes.

Unique themes and categories warrant highlighting. For example, the adolescents in this study described themselves as social enablers and engagers of reciprocity. These descriptions are unique contributions to research in that a great deal of research portrays these adolescents more as suppressed victims rather than social facilitators who contribute to the context in which they live. The unique theme of balanced, meaningful social relationships with peers and members in the adult world, these adolescents appreciating their support, perceive the social resources as instrumental, but wanting to be the social enabler and engage in negotiated collaboration warrants more attention. Overall, adolescents expressed the desire to be and act as agents of change.

These expressions offer insight into determining areas for improvement in adolescent-provider relations and warrant explorations of developmental influences on collaborations. Also, these examples provide evidence that adolescents appreciate the social facilitation and collaborations amongst themselves and members in their social structure, but also recognize their ability and capacity to be the social enablers and agents of change themselves. Furthermore, the examples demonstrate the essence for a balance between their voices being heard and being spoken to as well as being understood.

These interrelated beliefs and actions (e.g. reciprocity and enablement) among adolescents living with a mother with a mental disorder have not been presented in research to date. Further exploration of parental/familial, peers, educators, and providers
influence on the self-management of adolescents is needed. In addition, understanding the point during the developmental phases of greatest impact is indicated.

Although the study provided much insight about the contextual and individual-level self-management resources of adolescents of mothers with MD, limitations exist. Convenience sampling, restricted to one geographical location in South Florida, limits the generalizability of the study’s results. Also, since mothers who agreed to allow their children to participate may have been more positively involved in the adolescent’s life than mothers who were not involved, further limits generalizability. Finally, it is noteworthy that the questions in this study were designed to elicit positive responses because the aim was to understand the internal resources of these adolescents that help them to manage challenges. Questions more focused on the challenges of these adolescents may have elucidated more stories about their adversity and difficulties.

Despite study limitations, the strength-based, protective-focused approach of this study expands knowledge about the individual-level self-management resources of adolescents of mothers with a mental disorder. The Individual and Family Self-Management Theory has been applied previously to children living with chronic illnesses (Denison et al., 2015) but understudied among adolescents of mothers with MD. This study’s findings substantiate other research that accentuate family/caregiver and peer support and involvement as instrumental to healthy development and coping (Denison et al., 2015). While the significance of family involvement is undisputed among children living with chronic illnesses, explored less is the role of family, peers, and other members of the adult world (e.g. teachers and providers) as self-management enhancers as related to adolescents of mothers with MD. This study demonstrates, however, that self-
management efforts targeting adolescents of mothers with MD should not only involve family but also peers, teachers, and providers.

Furthermore, based on the findings of this study, adolescents of mothers with MD believe in their self-management capacity, possess self-regulation skills and abilities, and engage in self-management. These findings support other research that highlight the important role of self-regulation skills in health maintenance in the context of adolescents living with chronic illnesses (Berg et al., 2014). However, this study explores various forms of self-regulation in relation to adolescents of mothers with MD.

Implications for Research and Practice

Nurses are among those positioned at the forefront of serving adolescents of mothers with MD and are well-positioned to facilitate adolescent prevention and resiliency through enhancing self-management. This position affords nurses opportunities to promote self-management of these adolescents by 1) identifying self-management processes, 2) facilitating adolescent expression of their perspectives, 3) educating policymakers, school personnel about self-management resources (e.g. positive self-concepts, self-regulation, and positive social relationships), 4) educating adolescents and their families on self-management resources especially in the context of adversity and challenges, 5) facilitating adolescents’ and their families’ access to and utilization of self-management enhancing resources, and 6) strengthening self-management capacities of these adolescents and families. Community and public health nurses can also advocate for and promote adolescent self-management through their interactions with other adults who are central to the lives of at-risk adolescents, such as family, teachers, and health or social service providers. Family, juvenile justice systems, mental health, and school
health services should be encouraged to improve at-risk adolescent self-management resources and strategies by fostering collaborative relations marked with reciprocity. These relations could promote adolescent communication, engagement, treatment adherence and foster a health-promoting balance between the adolescent being enabled by others in their social structures and serving as the enabler, social contributor, and agent of change.

To address critical gaps in scientific knowledge, future research should explore at-risk adolescent self-management contextualized to the adolescent’s lived experiences and their impact on patterns of self-management, treatment adherence, and relevant health outcomes; self-management and levels of treatment adherence; and comparative effectiveness of alternative provider-based self-management interventions and their impact on health outcomes and service utilization and costs (Modi et al., 2012). Additionally, considering the developmental transitions during the period of adolescence and increased susceptibility to risky behaviors and mental problems, exploring impact levels of self-management promoting interventions, either family and/or health care system-based, throughout adolescence is much needed (Modi et al., 2012).

Although adolescence is a period of transitioning to autonomy and independence (American Academy, 2015; CDC, 2017), the study’s findings confirm the significance of maternal involvement and positive parenting as instrumental to adolescent resiliency, self-management, and positive development, and influential capacity of peers and members of the adult world (e.g. teachers and providers). This consideration would help establish efficacious, ecologically-driven, customized self-management treatment protocols tailored to meet the adolescent’s developmental need. Given risk factors
unique to living with a mother with a mental disorder, exploring self-management promoting, coordinated interventions across multiple contexts (family, health, social) deserves attention since coordinated interventions influence health outcomes more than those that are isolated (Modi et al., 2012). Online and social networking self-management interventions also should be explored (Modi et al., 2012), especially considering their influence in this era and accessibility, and for those adolescents who may be unreachable (some loss to contact for follow-up). For example, an interactive social application designed to foster self-management and connection with relevant resources may benefit adolescents of mothers with MD. Furthermore, exploring the influence of culture in self-management among minority populations is warranted given the tendency for their underrepresentation in clinical research (Modi et al., 2012). A comprehensive exploration of self-management resources through multiple facets (e.g. knowledge and beliefs, self-regulatory skills and behaviors, and meaningful social connections) among adolescents of mothers with MD through the adolescent’s perspective informs the development of efficacious, ecologically-based, primary, secondary, and tertiary prevention interventions and more optimal public health policies.

Conclusion

Understanding the lived experiences of adolescents of mothers with MD as the interplay of self-management knowledge and beliefs and behaviors provide insight into their resources and capabilities to manage stable and challenging times. Congruent with conceptualizations of the Individual and Family Self-Management Theory, the findings reveal self-management resources and skills that influence the thriving capacity and healthy development of adolescents of mothers with MD. Uncovered themes through the
perspective of these adolescents demonstrate evidence of the construction of healthy, positive self-concepts, various forms of self-regulation, and balanced socialization which represent their self-management resources.
CHAPTER 4: COMMUNITY-BASED RESEARCH WITH FAMILIES OF MOTHERS WITH A MENTAL DISORDER: LESSONS LEARNED

Background

Women are disproportionately affected by mental disorders (World Health Organization, 2016; National Institute of Health [NIH], 2016), which represent a large burden of disability on women worldwide (NIH, 2016; Whiteford et al., 2015) as well as adverse consequences for their families (Conners-Burrow et al., 2013; Hser et al., 2013; VanDeMark et al., 2005). The harmful effects of maternal mental disorders including substance use disorders, on children’s health is well documented (Conners-Burrow et al., 2013; Hser et al., 2013; VanDeMark et al., 2005). These children may be vulnerable due to disruptions in parenting (Arria et al., 2012; Dvir, 2012; Haggerty et al., 2008; Perera, Short, & Fernbacher, 2014), interruptions in their social support, family discord and separation related to loss of maternal custody, neglect (Atkins, 2010; Kohl et al., 2011), decreased parental monitoring and supervision (Latendresse et al., 2008; Stanger et al., 2004), and problematic parent-child interactions (Johnson, Cohen, Chen, Kasen, & Brook, 2006; Arria et al., 2012; Stanger et al., 2004). Given these reasons, the need to focus on these families as a susceptible group is among the highest national health priorities recognized by the Surgeon General in his 2016 report on health and substance abuse. Despite the need, family support services for these children and families are often inaccessible, further highlighting the urgency to focus on protecting and addressing the needs of these families.

There is a need for effective family-based interventions that can address family relationships and the context of risk for families of mothers with a maternal mental disorder. Children of mothers with mental disorders (MD) can be resilient (Leonard et
al., 2008; Criss et al., 2002), resistant to risky behaviors, and optimistic about obtaining a better future (Ronel & Levy-Cahana, 2011). Researchers have identified the family as an ideal setting that can serve as a buffer against mental, emotional, and physical health infirmities (Bell, 2012; Pequegnat and Stover 2000) and thus, significantly influence healthy individual outcomes.

Despite evidence indicating that improvements in family functioning and positive parenting may benefit mothers suffering from mental disorders and their children (USDHHS, 2014), rigorous family-based intervention or other longitudinal research for mothers with mental or substance use disorders and their children remains limited (Calhoun et al., 2015; Solis et al, 2012). Researchers have described the challenges of conducting family research with women with mental health or substance abuse problems, particularly the challenges of enrolling and retaining participants due to stigma associated with maternal mental health (Tryphonopoulos, 2015) as well as family instability and relocation (Mitrani et al., 2009).

The goal of this report is to present some of the methodological and logistical challenges encountered while conducting a community-based clinical trial testing the effectiveness of a home-based family-strengthening intervention for mothers with mental disorders and their children and an ancillary study conducting qualitative interviews with a subset of the youth with mothers enrolled in the clinical trial. We describe challenges related to 1) participant recruitment and retention, 2) participant burden, 3) participant service needs, 4) community provider engagement, and 5) protection of vulnerable participants. We present strategies employed to address each challenge area and the success or lack thereof in addressing these challenges.
Methods

The lessons learned in this report are based on experiences of the research teams while conducting two studies with a sample of mothers with MD and their children. The parent study was an NIH-funded randomized clinical trial, Healthy Home, with an ancillary qualitative dissertation study, Project I.M.P.A.C.T. Both studies were approved by the University of Miami’s IRB; the parent study received a Certificate of Confidentiality from the NIH. The majority of the issues described in this report arose in the parent study, but some challenges and lessons, particularly related to the protection of vulnerable participants, were derived from the ancillary study.

Healthy Home Study

This study compared a family-strengthening, nurse-led, home-based health intervention, "Healthy Home," as an enhancement to substance abuse or mental health outpatient treatment, with a control group receiving outpatient treatment as usual (TAU) among 172 mothers enrolled in outpatient substance abuse, mental health or case management services. The trial tested the effectiveness of Healthy Home in improving physical and mental health of the mothers and their children (ages 2-18), test mechanisms of action (self-care, environmental risk, family functioning and stigma), and assess implementation factors. The study was conducted with a community partner, Banyan Health Systems, which delivers behavioral health and primary care services. Banyan personnel were key members of the research team for participant recruitment/retention and data collection and for delivering the Healthy Home intervention. Data collection and intervention were conducted in the home or other setting, in English or Spanish, as
per participant preference, by bilingual study personnel. Data was collected via face to face interviews at baseline, 4, 8, and 12 months post-randomization.

The Healthy Home intervention, which is based on Structural Ecosystems Therapy (SET; Mitrani, Robinson, & Szapocznik, 2009; Mitrani et al., 2012), was delivered by nurses through family visits. Visits were planned to occur approximately once every two weeks for a period of four months and were ordinarily planned to include the mother, her children, and other person(s) from the family or support network as determined by the mother. During family visits, the nurse assessed the women, children, and other family members’ health needs, provided recommendations and education, and assisted with referrals and access to services.

Different subgroups of the study team met at three weekly meetings, which included: 1) a clinical meeting attended by the Healthy Home nurses, the clinical supervisor, and the principal investigator (who attended intermittently to monitor fidelity and redirect as needed), 2) a research coordination meeting attended by the recruitment/data collection team and the principal investigator, 3) a research methodology/publication meeting attended by the statistician, graduate students, and principal investigator (and which included Banyan personnel on an as-needed basis). This structure provided opportunities for ongoing interaction and joint decision-making between the university and Banyan personnel, facilitating a community-based participatory approach.

*Project I.M.P.A.C.T*

Project I.M.P.A.C.T. (Inspiring Minority Youth and Families to Positively Address Challenging Times) conducted qualitative interviews with 19 adolescents, aged
10-19 years (9 boys, 10 girls), of mothers enrolled in the parent study. The aim of the interviews was to explore protective factors among adolescents of mothers with MD. The interviews were conducted in a private area of the home, which afforded the adolescent privacy, and were audio-recorded. Parental permission and adolescent assent were obtained; mothers served as the gatekeepers between the interviewer and the adolescent (but were not present at the interview). The interviewer met with the study Healthy Home principal investigator on a weekly basis and consulted, as needed, to address challenges or issues that arose.

Data Sources and Analysis Plan for this Report

The information sources for this report included meeting notes, IRB modifications, study enrollment and contact logs and reports, and research team contact notes. Our analysis began with reviewing all IRB protocol modifications since these typically reflected changes to the protocol in response to challenges and the other data sources mentioned above. A table listing challenges, strategies to address the challenges, results, and recommendations/lessons learned was presented to study team members for their review and discussion until consensus was reached regarding the table contents. The challenges were organized into five categories: 1) participant recruitment and retention, 2) participant burden, 3) participant service needs, 4) community provider engagement, and 5) protection of vulnerable participants.

Results

Participant Recruitment and Retention

The parent study was designed to reduce barriers to participant recruitment and retention, which we knew in advance would be difficult due to the daily life hassles, emotional and material resource limitations, and the stigma associated with being a
mother with substance abuse or other mental health problem. The original plan was to exclusively recruit mothers receiving outpatient substance abuse treatment at Banyan, where recruitment material was posted, and to enlist Banyan behavioral health clinical personnel, who had an existing relationship with the mother, to provide a “warm handoff” of the study candidate to the study team. The Banyan clinician would broach the topic of the study, introduce the mother to the study team member if he or she was present at the clinic, or let the mother know the name of the study team member who would call her. The clinician also would help the study team with outreach to mothers who were hard to reach, although in many of these cases, the providers had difficulty reaching these participants. Interruptions in reliable transportation, phone service and housing stability, and caregiving demands appeared to influence the participation of the mothers and their children. Thus, procedures were designed to reduce transportation and child care-related barriers to participation, such as conducting screening and assessments by telephone and conducting informed consent and assessments in the participant’s homes. Monetary incentives also were used to make participation attractive.

While we were able to successfully use these strategies for recruitment, the plan was challenged by a smaller than expected pool of eligible study candidates. After three months of failing to meet our enrollment target, we began to expand eligibility criteria. We expanded eligibility criteria in several steps, as needed, to finally meet our enrollment target: 1) first, by including mothers even if they were not living with their children (as long as they had at least monthly contact), 2) next, by including mothers receiving outpatient substance abuse at agencies other than Banyan, 3) then, by including mothers receiving either substance abuse or other mental health outpatient treatment, and 4)
finally, by including mothers receiving case management services at Banyan for mental health disorders.

Expanding eligibility solved the participant accrual problem, but it introduced methodological and logistical challenges for the study. First, including mothers who were not in substance abuse treatment (62% of the sample were in other mental health treatment) reduced the study’s power to detect an effect on a key outcome measure planned for the study, i.e., reduction in substance abuse relapse. Second, including mothers receiving treatment at other agencies (15%) impacted the coordination between the study team and the referring agency personnel, both for research assessments as well as for the Healthy Home intervention.

As seen in Figure 5, the study team successfully retained participants, exceeding the planned rate of 75% retention at each time point. To date, retention rates for follow up are 80% at the 4 month time-point and 83% at the 8 and 12 month time-points, demonstrating that some participants who were lost to follow-up at an earlier time-point could be re-engaged later. The team strategized at the weekly study coordination meeting about how to maintain engagement or re-engage hard-to-reach participants using strategies described below. To ensure we kept track of our progress with recruitment and retention, the study team monitored efforts and results weekly and continuously updated documentation.

The overall approach for retention was for the study team to build a strong relationship with the mothers, which was forged through the time spent together at assessments. Retention was also accomplished by having ongoing contact with participants between assessment visits (e.g. mailed holiday, Mother’s Day and birthday
greeting cards, and appointment reminders) and having the same assessment team member as their contact throughout the study. A crucial element in relationship building was having bi-cultural (Hispanic American) assessors who demonstrated friendly, helpful, and non-judgmental attitudes towards the mothers and their children. The questionnaires were delivered in face-to-face interview format as a means of overcoming potential literacy limitations and to maximize participant engagement in the assessment process. Relationship-building with participants required sensitivity on the part of the assessors as the questions they asked regarding the family environment, mother-child relationships, and the mother’s mental health or substance use status were delicate topics subject to stigma. Building trust with the mothers was key for the mothers to grant us access to their personal information and their children, particularly in families where the mother was at risk for losing child custody. In addition, we continued to enlist the clinical staff of Banyan to assist with outreach and provide new contact information for mothers who had moved or changed telephone numbers. The assessment team members also reached out to family contacts the mothers had given us permission to reach and even did “drop by” visits to the mother’s home when they could not reach a participant by telephone.

**Participant Burden**

One of the important aspects of the study is that we enrolled and collected data from mothers and children. We planned to measure height, weight, and waist circumference in all children enrolled in the study; in addition, children ages 10-18 self-reported regarding their health and physical health and their relationship with their mother, using measures for which we had parallel reports about the children from the
mother. Having multi-reporter data is useful for understanding family processes and mitigates reporter bias. However, it also increased participant burden. Additionally, these women experienced competing time demands (treatment attendance, work schedule, child caregiving), which challenged their study participation. Mothers were responsible for gathering their children for the data collection appointments and completing mother-reported measures for each of their children. Data collection sessions could take anywhere from 1.5 hours to 4 hours for mothers and .5 hours to 1 hour per child. Our approach to mitigating this burden was to offer appointment times convenient to the family (including evenings and weekends), homebased assessments, bringing food, offering breaks, or breaking up assessments across different appointments. Our two assessors sometimes arrived at the assessment together so that mothers and children could be interviewed simultaneously.

The nature of some of the information being collected could be emotionally taxing to the mothers. For example, some mothers objected to a questionnaire that asked about their perceived stigma related to having a mental health or substance abuse problem (a label, specifically substance abuse, that some mothers rejected). Another measure asked about the mother’s history of maltreatment, which brought back painful memories for some of the mothers. Assessors’ nonjudgmental attitudes and empathetic listening helped to ameliorate the emotional burden, and licensed mental health professionals were available immediately for telephone consultation or to speak directly with participants.

As noted, our efforts to minimize participant burden required a flexible protocol that aimed to meet participant needs and address participant distress. Both assessors were
bi-cultural (Hispanic-American) women, which addressed our sample’s cultural representativeness (81% Hispanic). Once mothers realized this was their time, perceived her and her children were important, her concerns were heard, and rapport was built, it provided more incentive for research participation. Piloting of procedures and responding to participant reactions helped inform protocol revisions (e.g. adapting questionnaires so they related to participants; before implementing waist circumference measure with children, assessors asked kids, especially adolescents, how they felt).

Every week at the study coordination meeting, the study team discussed any participant burden-related issues that arose and determined whether any additional follow-up was needed with a particular family and whether a protocol modification was needed. For example, we modified the protocol to only administer the history of maltreatment measure at baseline rather than at all time-points because of the negative reaction of some of the mothers. Making this change meant that we could not assess whether there were new experiences of maltreatment during the course of the study, but as we were most interested in this construct as a moderator of treatment outcome, removing the measure at follow-up time-points was not a significant loss to the study.

The Healthy Home intervention also introduced participant burden for some mothers. Even though the intervention aimed to relieve mothers by helping them to garner emotional and instrumental support from family members and community services, having a nurse arrive at the home could be stressful and perceived as invasive for mothers, children, and other household members. This perception was seen particularly in families with moderate levels of conflict, those embarrassed by the condition of their homes, or mothers who had difficulty finding a time when they could
be present with their children or other family members. The original plan was for bi-weekly home visits over a 4-month period, which would begin upon assigning the case to a Healthy Home nurse.

As with other study procedures, we learned that we needed to be flexible in our intervention protocol. It could take weeks or even months to engage a mother for a first home visit. In response, we added an incentive for the first home visit in the form of a $20 gift card. We also delayed the start of the 4-month clock to begin at the first visit. In addition, some mothers informed the nurse that they desired less frequent visits. In response, we adapted the frequency of nurse visits to be set by the mother according to her needs and preferences. So as not to lose momentum in the intervention, the nurses began to supplement home visits with telephone calls. This change was congruent with the Healthy Home intervention model, which aimed to validate the mother’s autonomy and self-determination to decide what was best for her and her children. We aimed for Healthy Home to be a different experience for the mothers, in contrast to services mandated by child protective or other legal entities, as a means to validate her leadership of her family. We also were flexible in providing more frequent visits and a longer course of the intervention as needed. From a methodological perspective, this flexibility introduces variability in treatment dosage and timing, which has been documented and will be considered as part of the outcome analysis.

Participant Service Needs

Our participant population has a high level of social and health service needs. Over and above their mental health problems, the mothers faced extraordinary day-to-day life challenges, including precarious financial situations, unstable housing, and loss or
threatened loss of child custody. There were also the health and mental health problems of the children in some families, which, in some cases, were not being addressed. Helping the families access and effectively use services for these types of problems is one of the major foci of the Healthy Home intervention; however, we also had an ethical responsibility to assist the families assigned to the control arm of the study when we learned about such needs during the assessment procedures.

Since we used interviewer format rather than paper/pencil for data collection, the assessors learned things about participant needs, including hearing “stories” from participants beyond the answers to the questionnaires. The assessment team was well versed regarding available services at Banyan and in the local community; we also provided them with a directory of services to which they could refer mothers. At the team meetings, we discussed families with needs for which the assessment team did not have readily available referrals, and clinicians were available for families presented with pressing needs or crises.

We did our best to help the families, but we also had to manage their expectations. For instance, some mothers who experienced child custody loss asked if their study participation would guarantee them regaining child custody. Some asked if their mental status would improve as a result of the research participation. Thus, it was important to avoid false reassurances among this vulnerable population, despite service demands. To manage participant expectations, we engaged in realistic, open, and honest communication about the potential benefits of participating in the study, the limits of those benefits, and the possible risks, including mandated reporting of child abuse/neglect.
A challenge was addressing the high unmet needs of these families, in the intervention and control groups, and their gaps in resource accessibility. Across both groups, we found that basic necessities, such as food, housing, and transportation, were unmet at times and thus, were always top priority for these families. As a result, we often encountered service requests from these mothers, which we felt obligated to address. The protocol outlined steps for mental health referrals, but once we noticed other unmet needs, we implemented some approaches to address them. We provided mothers in the control group primary care service information as needed, a directory of available services, and enlisted the help of agency staff and providers (therapists, case managers, Healthy Home nurse interventionists) to effectively serve the mothers and children. Mothers in the intervention group received the same services in addition to the Healthy Home nurse interventionist performing ongoing outreach to resources/providers, guiding participants in interactions with resources/providers and with family to help with referral follow-through, and checking for referral follow-through. Additionally, in between visits, the interventionist nurse interacted with other service providers (e.g., counselor, health care providers) to help optimize the family’s service utilization and coordinate care. This addressed the families’ needs but posed logistical challenges and compromised methodology in that assessors were blinded by what exactly the nurse could do for participants regarding referrals, which impacts the study’s power to detect differences in effects across both groups.

Community Provider Engagement for Study Referrals and Continuity of Care

We originally had planned to work exclusively with Banyan patients, which would have meant that we only needed to engage providers from our research partner
agency to collaborate for participant recruitment, retention, and coordination of care. As mentioned above, due to slow subject accrual, we had to expand our recruitment beyond Banyan to other agencies in Miami-Dade County who provided substance abuse and other mental health outpatient services to women. This expansion proved to be highly challenging given extensive outreach endeavors which included phone calls, meetings, and presentations to agency administration and staff; in the end, only 15% of our sample came from other agencies, despite our extensive outreach efforts. The majority of our referrals from one agency came from one counselor with whom we were able to build and maintain rapport and who saw the value to her clients of receiving the Healthy Home intervention.

Protection of Vulnerable Subjects

Our study population included vulnerable mothers and their children who, as stated above, were subject to high risk life circumstances and a great deal of need. These issues were discussed at every clinical and study coordination meeting; sometimes, we were faced with questions that were ethically challenging. We were guided by the major principles of human subjects’ protection: respect for persons, justice, and beneficence in making determinations.

Respect requires that participants be fully informed and give consent to what will occur in the research and that their privacy be protected. We observed that boundaries of confidentiality functioned as challenges. Examples of these experiences include children being concerned about siblings eavesdropping, having to conduct interviews in small spaces, and women expressing concern that their live-in partners or others would overhear. Prior to or during assessments, some mothers expressed being in strained
relationships, which they were trying to leave and alerted assessors to their jealous partners and the partner’s planned presence at the assessment. The in home-based assessments facilitated research participation by going where the participants lived; however, this posed the risk of others hearing the participant’s private matters. To address this concern, assessors allowed the participant/respondent to point to responses (versus reading responses aloud) on the laptop, talked lower than usual, explained and re-iterated the confidential nature of the interview and politely asked for privacy, and reminded just the participant’s responses were recorded. These strategies seemed helpful as researchers were able to get the participant’s own answers and enforce a comfortable environment for disclosure.

Justice requires that benefits and risks be distributed in a manner that does not privilege one group unfairly over another. All adult mothers receiving outpatient behavioral services at Banyan and those that the study team learned about from the referrals from other agencies were offered participation and randomly assigned, thus meeting the minimum standards of justice. The challenge was in balancing the benefits between the intervention and control arm among this population of high-needs families. As mentioned above, we addressed this challenge in part by providing service referrals and information to mothers in the control arm of the study and equitable study incentives.

Beneficence requires that the researchers try to maximize benefit and minimize harm to participants. Situations arose when information disclosed warranted mandated reporting. These situations included reports about suicidal ideation or behavior. Initially, our protocol briefly outlined steps for this situation. To more effectively address these situations, we employed several strategies. We revised our protocol and consent
language to clarify procedures for participants reporting suicidal thoughts (e.g. those reporting being interviewed by an on-site license health professional or via phone or calling the Banyan Crisis Stabilization Unit). We also had a mental health provider/therapist available for support, which the assessors felt was an immense help for guiding the team on how to best approach situations.

Children of mothers with MD are a vulnerable population whose safeguards challenge recruitment, retention, and data collection efforts. We encountered moments when the child participant disclosed information that required mandated reporting. This posed challenges as we had to fulfill reporting obligations while maintaining respect for persons and the family’s integrity as some of these families already experienced adverse situations (Department of Children and Families involvement, family separations due to previous custody loss), family discord, and court scrutiny. To protect the confidentiality of children enrolled, mothers were explained that information the child provided remained confidential unless the team discovered the child to be in a dangerous situation. Researchers reported mother’s fear of child custody loss as a potential inhibitor to mothers enrolling their children into the study. For both studies, the assent included confidentiality-related language.

We adopted standardized protocols for explaining the study to potential participants, screening, and facilitating the informed consent process in both studies. Interactive and ongoing exchanges were made between the assessors and participants to facilitate participants’ understanding of “the reason for the study, description of procedures performed, participant responsibilities and time commitments, study benefits and potential risks, and how results will be utilized.” Check-ins occurred with the
mothers of the enrolled children to assess for concerns and questions. For both studies, mothers were approached prior to assent. For the ancillary study, the consent form provided options for the mother to be contacted prior to the follow-up call. For mothers who selected this option, the mother was called prior to the follow-up call with the child. It was important to send a message to the youth participating in the studies it was important for their voices to be heard but also to the mothers respect for their maternal role without appearing to disregard the mother’s parental power.

Ethical considerations remained at the forefront throughout our program of research. Given the economic strains and vulnerabilities of these families, we ensured equal resource distributions for both study groups (TAU and the intervention). Mothers in both groups received the same incentives. For example, mothers randomized to the treatment condition received $20 for the first family visit, and mothers in the control group were compensated as well. The study team was attentive to the possibility that the study’s incentives could unduly influence individuals to enroll in research, and thus compromise the voluntariness of consent and data integrity. Mothers across both conditions received referrals as needed. While these service referrals helped, at times the participant’s providers would change or were difficult to reach; therefore, the study team had to familiarize the roles of providers and understand their scope of work. Some mothers expressed frustrations with nurses being unable to help them in the way the therapist does. To address this, research meetings included nurse updates, which helped facilitate resolution.

The intersecting vulnerabilities among women with mental disorders and their children contribute to institutional trepidation of their involvement in research: a possible
contributing factor of their under-representation in research. Initially, the Institutional Review Board deferred the ancillary study’s protocol submission due to fears of volatile situations resulting from the adolescent interviews, concerns about coercion from “probing mothers,” and mothers being present during the interviews. In response, we modified the protocol to address such concerns by including more safeguards to protect the adolescent’s privacy and freedom from coercion.

Discussion

The following lessons learned summarize key themes researchers should consider while conducting community-based research with vulnerable populations, such as mothers with mental disorders and their children.

Lesson one: Building Relationships with Members of Vulnerable Populations

Building strong relationships with the participants facilitated participant retention. Addressing life stressors and demands and understanding how these impact the resources of mothers (Mellins et al., 2003) facilitated recruitment and retention. These mothers were often placed in situations where demands exceed their resources, and experience accentuated vulnerabilities due to traumatic experiences and unmet basic necessities. Thus, it became our lesson to empathetically listen with nonjudgmental attitudes, understand the stressors and demands of these mother and children that inhibited their participation in the research, and adapt the protocol to meet their needs when possible.

Lesson two: Community Provider Engagement Comes When Seeing the Value to their Clients

Engaging community providers was an intricate process integral to recruitment and study buy-in that required breaking through resistance among providers and devoting
immense attention to not just methodological rigor but also agency culture and contextual realities. A balance between all entities was critical. To facilitate community provider engagement, points of contacts were established and frequent outreach was conducted to site liaisons. Despite such strategies, recruitment was very low at 3 of the 4 agencies, with one agency providing most referrals (86%). One agency refused the offer for a partnership for unspecified reasons. Such reluctance among community providers to engage in family research among mothers with MD and their children needs further exploration. This reluctance may be partly due to fear of disrupted provider-participant relations, lack of time, discomfort with study procedures, and/or forgetting about the study (Howard et al., 2009). We learned the best relationships with agency personnel came when the study’s value to their clients was clear.

Fostering ongoing mutual collaborations played an integral role. The team learned the importance of valuing the contributions of the community agency providers. Although the recruitment goal was reached and retention rates successful, an extraordinary level of coordination and cooperation among the research team and agency personnel were needed. Additionally, creating a forum where every team member’s input was valued and opinion sought was an impetus to conduct the research. Based on interactions amongst researchers and the community agency personnel, we recognized community based participatory research is about reciprocity on both, the researchers and community agency sides, that benefits both. For the researchers, the gain is about having community cooperation to help with participant recruitment, retention and coordination of services; for the agency, it’s about providing a service that is valuable to their clients.
Sometimes an agency doesn’t feel that it’s worth the trouble to give access to their clients – or they are protecting their clients.

Lesson three: Organized Flexibility

Flexibility was needed but also led to some compromises that weakened some of the methodological aspects of the study. Another strategy facilitating study success/implementation was maintaining a balance between scientific rigor and feasibility based on consensus reached between academic and community provider institutions. From a methodological perspective, this flexibility introduced variability in treatment dosage, which has been documented and will be considered part of the outcome analysis.

A strategy to help maximize feasibility and acceptability included piloting and detailed documentation of procedures. Some key ingredients to conducting our program of research were clear policies and ongoing documentation illustrating study progress. Piloting helped reconcile practical difficulties; appraise participant burden and taxation; appraise burden on community agency partners; and, fine-tune logistics. Detailed recruitment strategies and ongoing evaluation of approaches seemed to “maximize the success of retention and recruitment methods and efficient resource expenditure.”

Conclusion

This report described challenges we experienced, along with strategies to consider when conducting community-based, family research among women with MD and their children. Conducting research among mothers with MD and their children poses multi-level challenges, yet is critical. These research efforts, however, involve understanding the context of these families, learning the culture of partnered community agencies, and
developing flexible protocols to adapt and overcome research challenges. As we reflect on what was learned from the challenge areas of participant recruitment and retention barriers, participant burden, client service needs, community provider engagement, and protection of vulnerable participants, we derived lessons about adapting to the needs of the participants and community agency’s culture, fostering ongoing mutual collaborations, and piloting and detailed documentation of study procedures are key to research success. We recommend that researchers serving families affected by MD consider strategies to build relationships with members of these families to facilitate their research participation and retention. Researchers should be mindful that engaging community providers should entail making explicit the value to the provider’s clients. Furthermore, researchers should remember that organized flexibility should be continuously performed throughout so necessary revisions are made and continually evaluated. These may be of value for researchers considering this challenging but important line of research.
CHAPTER 5: DISCUSSION

Major Dissertation Findings

The overall aim of the dissertation was to examine protective factors that can mitigate the risks to adolescents (ages 10-19) affected by maternal mental disorders (MD). This dissertation is presented through three manuscripts. Manuscript 1 (Chapter 2) presents the quantitative study, which applied Ecodevelopmental Theory (Prado et al., 2012), in conducting secondary analysis using baseline data from 90 mothers and 118 adolescents (ages 10-17 years) of mothers from the parent study, an ongoing randomized trial of a nurse-led home-health intervention. Manuscript 2 (Chapter 3) presents the qualitative study, which applied Individual and Family Self-Management Theory (Ryan & Sawin, 2009) in conducting semi-structured interviews with 19 adolescents (ages 10-19) of mothers from the parent study to gain the adolescents’ perspectives regarding their abilities to self-manage. Manuscript 3 (Chapter 4) presents lessons learned in conducting community-based research with families affected by maternal MD.

Conclusions from Manuscripts 1 and 2: Protective Factors for Adolescents Affected by Maternal Mental Disorders

Both studies highlight the protective capacity of mother’s positive parenting. In the quantitative study, mother’s involvement protected against adolescent internalizing and externalizing problems. Among all predictors, which included mother’s psychological functioning and substance use, parental involvement had the greatest impact on adolescent internalizing and externalizing problems. Parental involvement produced more of a change in adolescent externalizing problems than did mother’s substance use. In the qualitative study, mother’s involvement emerged as a subtheme, “Mothers as Cultivators - Positive Parenting Practices.” Mother’s involvement was described by
adolescents as a self-management enhancer. Adolescents described their mother as “the main support system”, critical to their wellbeing, coping, and adaptation. Adolescents described the positive impact of moments with their mother, including communication, confiding in her, and mother showing affection and responding to their needs.

Conclusions from Manuscripts 1 and 2: The Impact of Mother’s MD on Adolescent Wellbeing and Functioning

Another finding across both studies in this dissertation is the influence of the mother’s mental health problems on adolescent mental wellbeing and functioning. In the quantitative study, mother’s psychological distress was related to adolescent internalizing, and mother’s substance use was related to adolescent externalizing problems. In the qualitative study, adolescents reported self-management strategies, which entailed using internal resources to self-regulate and resolve situational and environmental demands associated with their mother’s distress. These strategies involve psychological, cognitive-responsive strategies (e.g. emotion regulation, self-containment, and directed focus) and behavioral strategies (e.g. symptom management and stress outlets). Through self-regulatory processes such as managing their response after appraising their mother’s distress, and reciprocal processes, undertaking a caring role to help their mothers who care for them, these adolescents accommodate their mothers.

Conclusions from Manuscript 3: Lessons Learned Conducting Research

Conducting community-based, family research among women with MD and their children is important, but challenging. In sum, the three main “lessons learned” that surfaced during research efforts were related to: 1) building relationships with members of vulnerable populations; 2) community provider engagement when seeing the value to their clients; and 3) organized flexibility.
Building relationships with clients and community providers is vital to achieving recruitment, retention, and engagement success, and investigators should consider several essential approaches related to overcome study-related barriers that hinder study success. Firstly, relationships with participant members of vulnerable populations should be empathetic, nonjudgmental and responsive to the contextual needs and demands of these families (e.g. convenient home-based, phone assessments, resource/service referrals). Intricate processes of community provider engagement including elucidating the study’s value to the agency’s clients and fostering mutual input where all contributions are valued is critical. These strategies were integral to recruitment and community partner buy-in/participation, yet, this required immense attention to methodological rigor (e.g. effect on study outcome analyses) and agency culture, and an extraordinary level of coordination and cooperation among the academic and agency personnel. Finally, investigators should make every effort to develop research studies that maximize participant and community engagement through ongoing research efforts and processes that minimize participant burden and harm, and maximize participant benefits, in addition to equally distributing/providing services (e.g. across study groups) while maintaining respect for persons of this vulnerable population.

The context of these families (e.g. resource limitations, daily life hassles, caregiving and time demands, and stigma) required the study team to be responsive to client and agency needs and organized flexibility in the study protocol and procedures. Clear policies and standard operating procedures, fine-tuning procedures through piloting, continuous feedback and problem solving involving every member of the study team, and ongoing study progress documentation were key in addressing pragmatic
difficulties. However, addressing these issues also sometimes entailed methodological compromises. For example, expanding study eligibility beyond mothers in substance abuse recovery solved the problem of participant accrual but reduced the study’s power to detect an effect on a key outcome measure of substance abuse relapse.

Limitations

Limitations should be considered when interpreting the results of the three manuscripts of this dissertation. The quantitative study’s cross-sectional design limits inferences associated with the direction of relationships and did not allow us to assess mother and child reciprocal processes. In addition, the quantitative study is limited to the mother’s report, thus subject to bias. The qualitative study used a strength-based approach and the questions were likely to have influenced the adolescents to focus on the positive. Although this is not a weakness of the study, per se, it is possible that more descriptions about adversities these adolescents face may have surfaced with a different approach. In addition, the interviews for the qualitative study were mostly conducted in the mother’s home, which may have influenced adolescents’ responses. Similarly, the mothers were the gatekeepers to the adolescents’ participation, and we therefore had a selected sample of adolescents. Finally, with respect to both the quantitative and qualitative studies, the age range (ages 10-18/19) represents a variety of developmental stages within adolescence with distinct cognitive, social/emotional, physiological, physical, and interpersonal transitions. The quantitative study did not investigate differences at the age-subgroup levels. In the qualitative study, although self-management beliefs and behaviors were mentioned, overall, by all the adolescents, worth mentioning is that adolescent’s self-management experience could likely differ
depending on advanced age offering more hindsight and, the length of exposure to maternal mental problem; however, no questions asked the duration of the maternal mental disorder exposure.

Future Direction

Future research is needed to inform interventions to protect the wellbeing of adolescents of mothers with MD. Longitudinal research would be useful for clarifying the processes that take place between maternal MD, parenting and adolescent mental health status. Also, future research should examine other drivers of parenting processes not tested here, such as social support or the presence of other parental figures, as well as examining the underlying factors that predict both maternal and child emotional functioning. Further research is needed to understand the challenges of various adolescent age groups to inform effective interventions tailored to their developmental needs contextualized to their experiences.

Implications for Nursing Practice

The findings from the three manuscripts of this dissertation have several implications for nursing practice. The findings underscore that promoting parental involvement in the lives of at-risk adolescents may bolster adolescent mental wellbeing. Also, it is important for providers working with mothers with MD and their children to recognize mental health related stressors on mothers so that appropriate resources are provided to parents in order for more attention to be given to the adolescent. Additionally, as suggested by this dissertation, listening to the voices of these adolescents and promoting their involvement in collaborations while using an ecologically-based approach to tailor interventions to their self-management resources may protect their
wellbeing and development. Furthermore, ethical considerations to protect these vulnerable families while being served should remain at the forefront of care and service delivery.
References


Bell, Carl C.; McBride, Dominica F. (2012). In: *Family and HIV/AIDS: Cultural and contextual issues in prevention and treatment*. Pequegnat, Willo (Ed); Bell, Carl C. (Ed); Publisher: Springer Science + Business Media; pp. 47-68. [Chapter], Database: PsycINFO


FIGURES

Figure 1. Integrated Theoretical Framework in the Context of Adolescents of Mothers with Mental Disorders.

- **Context: Risk and Protective Factors**
  - Mother’s Psychological Distress: mother’s life stress, anxiety, depression; and, mother’s substance use

- **Self-management Processes**
  - The Construction of Healthy, Positive Self-Concepts - Self Management Knowledge and Beliefs
  - The Capacity to Control the Outcomes of Life’s Events
  - Use of Internal Resources
  - Use of External Resources
  - Resolving Demands – Engaging in Various Forms of Self-Regulation during normal and challenging situations
  - Balanced Socialization – The Interplay between Individualism and Meaningful Social Connections
  - Family, Peers, Teachers, and Providers as Self-Management
  - Participation as a Member in Social Structures
  - Mothers as Cultivators

- **Proximal Outcome**
  - Self-Management Behaviors and Engagement

- **Distal Outcome**
  - Adolescent Mental Well-Being

- **Exosystem**

- **Microsystem**
Figure 2. Hypothesized SEM model in predicting adolescent mental problems
Figure 3. Results of the Hypothesized SEM model in predicting mental problems

Note. ** $p < .01$, *** $p < .001$. 
**Figure 4.** Grouping of Themes and Subthemes

### Theme 1:
The Construction of Healthy, Positive Self-Concepts – Self-Management Knowledge and Beliefs

- **Self-efficacy** (including goal setting)
- The Capacity to Control the Outcomes of Life’s Events - Choosing the Good View, Positive Thinking
- Use of Internal Resources – Self, Situational and Environmental Appraisal (e.g. directing their focus, self-containment, and emotional control)
- Use of External Resources (e.g. symptom management, medication adherence, outlets of stress)
- Family, Peers, Teachers, and Providers as Self-Management Enhancers
- Mothers as Cultivators - Positive Parenting Practices
- Participation as a Member in Social Structures – Making a Contribution and the Power of Expression (e.g. moments of speaking up)

### Theme 2:
Resolving Demands – Engaging in Various Forms of Self-Regulation during normal and challenging situations

- Use of Internal Resources – Self, Situational and Environmental Appraisal (e.g. directing their focus, self-containment, and emotional control)
- Use of External Resources (e.g. symptom management, medication adherence, outlets of stress)

### Theme 3:
Balanced Socialization – The Interplay between Individualism and Meaningful Social Connections

- Use of Internal Resources – Self, Situational and Environmental Appraisal (e.g. directing their focus, self-containment, and emotional control)
- Use of External Resources (e.g. symptom management, medication adherence, outlets of stress)
Figure 5. Participant flow through study

**Enrollment**
- Assessed for eligibility (n = 243)
  - Randomized (n = 173)
    - Excluded (n = 70)
      - Did not meet inclusion criteria (n = 9)
      - Declined to participate (n = 32)
      - Lost contact (n = 29)
  - Allocated to Healthy Home (n = 86)
    - Received at least 1 home visit (n = 76)
    - Received no (0) home visits (n = 9)
    - Withdrew from study prior to nurse assignment (n = 1)
  - Allocated to TAU (n = 87)
    - No study-related intervention

**Allocation**
- Completed Assessment (n = 68, 79%)
  - Follow-Up 1 4 months
- Completed Assessment (n = 71, 83%)
  - Follow-Up 2 8 months
- Completed Assessment (n = 69, 80%)
  - Follow-Up 3 12 months
- Analyzed (n = 85)
  - Excluded from analysis (n = 1); participant withdrew from study

- Completed Assessment (n = 69, 79%)
- Completed Assessment (n = 69, 79%)
- Completed Assessment (n = 69, 79%)
- Analyzed (n = 87)
  - Excluded from analysis (n = 0)
## TABLES

### Table 1

**Characteristics of Mothers**

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N  (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Race/Ethnicity</strong></td>
<td></td>
</tr>
<tr>
<td>Hispanic White</td>
<td>73 (81.1%)</td>
</tr>
<tr>
<td>Hispanic Black</td>
<td>3 (3.3%)</td>
</tr>
<tr>
<td>Non-Hispanic, White</td>
<td>4 (4.4%)</td>
</tr>
<tr>
<td>Non-Hispanic, Black</td>
<td>9 (10.0%)</td>
</tr>
<tr>
<td>Other</td>
<td>1 (1.1%)</td>
</tr>
<tr>
<td><strong>Monthly Income &lt;$1,000</strong></td>
<td>36 (40%)</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>(M=39.8; SD=7.9)</td>
<td></td>
</tr>
<tr>
<td><strong>Years of Education</strong></td>
<td></td>
</tr>
<tr>
<td>&lt;=11</td>
<td>33 (36.7%)</td>
</tr>
<tr>
<td>12</td>
<td>30 (33.3%)</td>
</tr>
<tr>
<td>&gt;12,&lt;16</td>
<td>18 (20%)</td>
</tr>
<tr>
<td>&gt;=16</td>
<td>7 (7.7%)</td>
</tr>
<tr>
<td><strong>Birthplace</strong></td>
<td></td>
</tr>
<tr>
<td>US</td>
<td>23 (25.6%)</td>
</tr>
<tr>
<td>Cuba</td>
<td>36 (40.0%)</td>
</tr>
<tr>
<td>Other (across 12 Latin American countries)</td>
<td>31 (34.4%)</td>
</tr>
</tbody>
</table>
Table 1 Continued

*Characteristics of Mothers*

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N  (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Employment Status</strong></td>
<td></td>
</tr>
<tr>
<td>Currently Not Employed</td>
<td>72 (80%)</td>
</tr>
<tr>
<td>Currently Employed</td>
<td>17 (19%)</td>
</tr>
<tr>
<td><strong>Current Relationship Status</strong></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>34 (37.8%)</td>
</tr>
<tr>
<td>Relationship, not legally married</td>
<td>11 (12.2%)</td>
</tr>
<tr>
<td>Married</td>
<td>14 (15.6%)</td>
</tr>
<tr>
<td>Divorced</td>
<td>16 (17.8%)</td>
</tr>
<tr>
<td>Separated</td>
<td>13 (14.4%)</td>
</tr>
<tr>
<td>Widowed</td>
<td>2 (2.2%)</td>
</tr>
<tr>
<td><strong>Type of Treatment</strong></td>
<td></td>
</tr>
<tr>
<td>In Substance Use Treatment</td>
<td>26 (28.9%)</td>
</tr>
<tr>
<td>In Mental Health Treatment</td>
<td>62 (68.9%)</td>
</tr>
</tbody>
</table>
Table 1 Continued

*Characteristics of Mothers*

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>N  (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Type of Diagnoses</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Primary Diagnosis</strong></td>
<td></td>
</tr>
<tr>
<td>Psychosis(^a)</td>
<td>41 (52%)</td>
</tr>
<tr>
<td>Mood/Anxiety Disorder(^a)</td>
<td>15 (19%)</td>
</tr>
<tr>
<td>Substance Use Disorder(^a)</td>
<td>23 (29%)</td>
</tr>
<tr>
<td><strong>Secondary Diagnosis</strong></td>
<td></td>
</tr>
<tr>
<td>Psychosis(^a)</td>
<td>3 (20%)</td>
</tr>
<tr>
<td>Mood/Anxiety Disorder(^a)</td>
<td>10 (67%)</td>
</tr>
<tr>
<td>Substance Use Disorder(^a)</td>
<td>2 (13%)</td>
</tr>
<tr>
<td>Other/Unreported(^a)</td>
<td>2 (100%)</td>
</tr>
</tbody>
</table>

*Note:* \(^a\) denotes grouped disorders.
Table 2

*Characteristics of Children Reported on by the Mothers*

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>95 (80.5%)</td>
</tr>
<tr>
<td>Non-Hispanic</td>
<td>13 (11.0%)</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td>(M=12.65; SD= 2.1)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>57 (48.3%)</td>
</tr>
<tr>
<td>Female</td>
<td>61 (51.7%)</td>
</tr>
<tr>
<td><strong>Living with Mom</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>96 (81.4%)</td>
</tr>
<tr>
<td>No</td>
<td>22 (18.6%)</td>
</tr>
<tr>
<td><strong>Country of Birth</strong></td>
<td></td>
</tr>
<tr>
<td>United States</td>
<td>91 (77.1%)</td>
</tr>
<tr>
<td>Other</td>
<td>23 (19.5%)</td>
</tr>
<tr>
<td><strong>Language Child Understands Better</strong></td>
<td></td>
</tr>
<tr>
<td>English</td>
<td>62 (52.5%)</td>
</tr>
<tr>
<td>Spanish</td>
<td>2 (1.7%)</td>
</tr>
<tr>
<td>Both</td>
<td>50 (42.4%)</td>
</tr>
<tr>
<td><strong>Grade in School</strong></td>
<td>(M = 6.9; SD = 2.19)</td>
</tr>
</tbody>
</table>
Table 2 Continued

*Characteristics of Children Reported on by the Mothers*

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Relationship to Mother</strong></td>
<td></td>
</tr>
<tr>
<td>Oldest Daughter</td>
<td>44 (37.3%)</td>
</tr>
<tr>
<td>Oldest Son</td>
<td>37 (31.4%)</td>
</tr>
<tr>
<td>Other *</td>
<td>1 (.8%)</td>
</tr>
<tr>
<td>Second Oldest Daughter</td>
<td>15 (12.7%)</td>
</tr>
<tr>
<td>Second Oldest Son</td>
<td>17 (14.4%)</td>
</tr>
<tr>
<td>Youngest Daughter</td>
<td>1 (.8%)</td>
</tr>
<tr>
<td>Youngest Son</td>
<td>3 (2.5%)</td>
</tr>
</tbody>
</table>

*Note: The “Other” is the mother’s biological child.*
Table 3

*The Relationship Between Psychological Distress, Positive Parenting Practices, and Adolescent Mental Wellbeing Among a Sample of Adolescents of Mothers with Mental Disorders*

(Mothers, N= 90; Adolescent N=118).

<table>
<thead>
<tr>
<th></th>
<th>Internalizing Problems</th>
<th>Externalizing Problems</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Unstandardized</td>
<td>Standardized</td>
</tr>
<tr>
<td></td>
<td>Coefficients</td>
<td>Coefficients</td>
</tr>
<tr>
<td><strong>Mother’s Psychological Distress</strong></td>
<td>4.33</td>
<td>1.29</td>
</tr>
<tr>
<td><strong>Mother’s Substance Use</strong></td>
<td>0.97</td>
<td>3.93</td>
</tr>
<tr>
<td><strong>Parental Involvement</strong></td>
<td>-4.53</td>
<td>1.59</td>
</tr>
<tr>
<td><strong>Positive Parenting</strong></td>
<td>0.97</td>
<td>1.67</td>
</tr>
</tbody>
</table>

*Note.* **p < .01, ***p < .001
Table 4

The Relationship Between Mother’s Psychological Distress and Substance Use and Positive Parenting Practices Among a Sample of Adolescents of Mothers with Mental Disorders

(Mothers, N= 90; Adolescent N=118).

<table>
<thead>
<tr>
<th></th>
<th>Parental Involvement</th>
<th>Positive Parenting</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Unstandardized</td>
<td>Standardized</td>
</tr>
<tr>
<td></td>
<td>Coefficients</td>
<td>Coefficients</td>
</tr>
<tr>
<td></td>
<td>B        SE    Beta</td>
<td>p</td>
</tr>
<tr>
<td>Mother’s Psychological Distress</td>
<td>0.03 0.15 0.03 0.845</td>
<td>0.09 0.16 0.09 0.586</td>
</tr>
<tr>
<td>Mother’s Substance Use</td>
<td>-0.21 0.50 -0.06 0.675</td>
<td>0.14 0.55 0.04 0.805</td>
</tr>
</tbody>
</table>
Table 5

*Gender and Race/Ethnicity Frequency Distribution by Age Group*

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Hispanic, Caucasian (n=13)</th>
<th>Non-Hispanic, African American (n=4)</th>
<th>Hispanic, Bi-racial (n=1)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Female (n=7)</td>
<td>Male (n=6)</td>
<td>Female (n=3)</td>
</tr>
<tr>
<td>10 to 14</td>
<td>5</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>15 to 16</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>17 to 21</td>
<td>0</td>
<td>NS</td>
</tr>
</tbody>
</table>

*Note.* NS indicates not specified. The sample included one Hispanic male adolescent whose race was not specified on the demographic form.
Table 6

*Themes, Categories, and Subcategories: Definition of Concepts*

<table>
<thead>
<tr>
<th>Concept</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge and Beliefs</td>
<td>Objective information and subjective perceptions about health status or behavior.</td>
</tr>
<tr>
<td>Self-efficacy</td>
<td>Relates to the level of confidence in successfully employing a behavior during normal and adversarial circumstances.</td>
</tr>
<tr>
<td>Self-Motivation</td>
<td>The intrinsic drive to employ strategies to seek individual goals</td>
</tr>
<tr>
<td>Self-Confidence</td>
<td>a self-perception of one’s belief in self abilities, dependent upon contextual background and setting. An individual’s trust in his/her ability to achieve a goal.</td>
</tr>
<tr>
<td>Positive self-concept</td>
<td>The subjective perception of the self-system in its entirety- various domains including learned beliefs, attitudes and opinions the individual believes to be true about him/herself.</td>
</tr>
<tr>
<td>Self-sufficiency</td>
<td>The ability to support oneself without depending on external resources.</td>
</tr>
<tr>
<td>Outcome Expectancy</td>
<td>The belief that employing a specific behavior will yield preferred outcomes.</td>
</tr>
<tr>
<td>Internal locus of control</td>
<td>The extent an individual believes life’s outcomes are under their control.</td>
</tr>
<tr>
<td>Self-esteem</td>
<td>Feelings of personal worth and level of satisfaction regarding one's self.</td>
</tr>
<tr>
<td>Goal Congruence</td>
<td>The ability to resolve confusion and anxiety resulting from contradictory and competing demands associated with goals.</td>
</tr>
<tr>
<td>Resiliency/Overcoming Adversity</td>
<td>The ability to withstand adverse circumstances.</td>
</tr>
</tbody>
</table>
Table 6 Continued

<table>
<thead>
<tr>
<th>Sense of Agency</th>
<th>The ability to intentionally influence one’s functioning and the course of environmental events.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Optimism</td>
<td>Relates to the expectancy of positive life outcomes.</td>
</tr>
<tr>
<td>Self-Regulation</td>
<td>An iterative process individuals engage to achieve a change in health-related behaviors including various skills and abilities.</td>
</tr>
<tr>
<td>Goal Setting</td>
<td>A self-regulation skill/ability</td>
</tr>
<tr>
<td>Self-Monitoring and Reflective thinking</td>
<td>A self-regulation skill/ability</td>
</tr>
<tr>
<td>Decision Making</td>
<td>A self-regulation skill/ability</td>
</tr>
<tr>
<td>Planning and Action</td>
<td>A self-regulation skill/ability</td>
</tr>
<tr>
<td>Self-evaluation</td>
<td>A self-regulation skill/ability</td>
</tr>
<tr>
<td>Management of Response</td>
<td>A self-regulation skill/ability</td>
</tr>
<tr>
<td>Social Facilitation</td>
<td>Occurs within relationships and enhances the capacity to change</td>
</tr>
<tr>
<td>Social influence</td>
<td>Dialogues in which respected persons in positions of perceived authority with expert knowledge advises and encourages individuals to engage in health-related behaviors</td>
</tr>
<tr>
<td>Social support</td>
<td>Emotional, instrumental, or international support provided with the explicit goal of assisting engagement in healthy behaviors.</td>
</tr>
<tr>
<td>Negotiated collaboration</td>
<td>Occurs when multiple perspectives (your, mine, and our) are respected and influential.</td>
</tr>
<tr>
<td>Self-Management Behaviors</td>
<td>Behaviors including engagement in activities/treatment regimens, symptom management, or use of recommended pharmacological therapies.</td>
</tr>
<tr>
<td>Reciprocity</td>
<td>Is based on exchange and relates to the cooperative and moral behavior of the individual in that situation.</td>
</tr>
</tbody>
</table>
Table 6 Continued

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reciprocity</td>
<td>This system warrants both efficient distribution of scarce resources and mutual assistance in time of need.</td>
</tr>
<tr>
<td>Social Capital</td>
<td>Resources and opportunities available through interpersonal relationships and connections to resource-rich social networks that provide access to important information and guidance. “Social capital represents the idea that individuals may accrue benefits by participating as a member of social structures (Portes, 1998).”</td>
</tr>
<tr>
<td>Reciprocal Expectations</td>
<td>This term relates to the individual’s subjective evaluations of interpersonal acts and consequences of other’s actions for his/her own expectations. Also, it relates to mutual expectations of each party across situations or contexts.</td>
</tr>
<tr>
<td>Reciprocal Determinism</td>
<td>Expectancies postulate behavior; reciprocal effects between expectancy and behavior.</td>
</tr>
<tr>
<td>Family Resourcefulness</td>
<td>Involves enlisting help from others to cope with challenges and/or when an individual is unable to function autonomously.</td>
</tr>
<tr>
<td>Family Cohesion</td>
<td>The adolescent’s perception of bonding, togetherness, connectedness, support, and openness among family members.</td>
</tr>
<tr>
<td>Family Capacity</td>
<td>The family’s ability to endure and rebound from challenging situations.</td>
</tr>
</tbody>
</table>

Table 6 Continued


The following are represented: concepts of themes as major headings, concepts of categories as sub-headings with indented text, and concepts of subcategories as subheadings with the most indentation.
Appendix A: Adolescent Interview Questions

Interview Questions for the Adolescents in the Qualitative Study

A. **Questions to Build Rapport** *(starting on the positive side, gaining insight to their positive traits and self-management)*

1. What is your age?
2. When were you born?
3. Where were you born?
4. Where do you attend school?
5. How is school? **Probe:** What do you like about school? What do you not like about school? What subjects do you do well in—meaning the ones you get A’s and B’s in? What is your favorite class at school?
6. Tell me about your teachers. **Probe:** Does your mother know your teachers? Has your mother talked with your teachers before? About what kinds of things? I remember when my mother talked to my teacher too, it was…for me too.
7. What do you like to do in your free time? **Probe to build rapport:** What are your hobbies—like things you do for fun? What do you find yourself spending the most time doing?
8. What are some things that you are a good at? **Probe:** How did you get so good at it? Did you teach yourself? Who taught you?
   a. Do you play any sports? **Probe:** How long have you played? How does your mother react when she sees you play?
9. Who do you live with now?
10. Now let’s talk about your family. Tell me some things about your family. Do you have any brothers or sisters?
11. How old are they? So that makes you the [oldest, youngest, middle, second oldest] right? How is it being the [oldest/middle child/youngest]?
12. Tell me about the relationships with your [brother(s) and/or sister(s)]? How would you describe your relationship with your brother(s) and sister(s)? How much time do you spend with them? What are some things you like about your family? What do you enjoy doing with your family?
13. Now let’s talk about you. Tell me some things about yourself. **Interviewer ease into these questions.**

B. **Questions about Parenting Practices** *(learning about relationship with mother and her parenting style)*

14. I want to learn about the relationship you have with your mom and the time you spend together.
   a. What kinds of things do you and your mother do together? **Probe:** Tell me about a time when you and your mom did something together.
   b. What kinds of things do you talk about with your mom? **Probe:** Tell me about a time when you told your mom something that you did good, for example when you did good in school or made a good decision. How did she react?
15. What are the types of things you do that make her happy? **Probe:** How does she show you that she’s happy or proud of you? What are the things you do that make her unhappy with you?

16. What does your mom do that makes you happy or proud? **Probe:** How do you show her that you’re happy or proud of her?

17. How important is it for your mother to be involved in your life? **Probe:** Tell me why you think it is important that your mother is involved in your life. Who else do you think is important to be involved in your life? What is it about that person that makes them important to you?

C. **Questions about Self-management**

18. Tell me about a time you had to handle something bad that happened? Tell me about a time when something bad happened but you were able to make it positive? (adapted from the Self-Efficacy Questionnaire for Children (SEQ-C); assessing self-efficacy) **Probe:** How did you learn the skills to do something good/be positive when bad things happen? Would you say that no matter what happens, you can get something good from it? (assessing self-efficacy)

19. What are some of your goals? **Probe:** Do you think it’s important to have goals, why? **Probe:** When you are excited about reaching a goal, what do you do? (adapted from Questionnaire on Self-Regulation; assessing self-regulation)

20. What do you do when you feel mad? (adapted from Questionnaire on Self-Regulation; adapted from Questionnaire on Self-Regulation; assessing self-regulation)

21. Tell me about a time you were able to stay focused when things were going on around you (adapted from the Adolescent Self-Regulatory Inventory; assessing self-regulation)

D. **Question about factors that contribute to their ability to overcome adverse experiences (ending on more positive note)**

23. What are some things that help you when you are stressed or upset? **Probe:** How do these things help you not focus on the bad? Who taught you how to do these things?