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Experiences of Colorado Parents as They Recognized Their Child's Mental Illness

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Abstract

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MPA, City University, 1997

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Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Philosophy
Public Policy and Administration

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Abstract

Mental illness is not only the leading cause of disability among adults, but there is also an emerging public health crisis in childhood mental illness. A majority of parents do not recognize symptoms of psychological disorder in their children, and current policies and programs for mental health service delivery are not sufficiently responsive to the early help-seeking dynamics of families. Using a concurrent mixed methods design, this study explored how parents in the Pikes Peak region of Colorado learned to recognize their child's mental illness. Phenomenological interviews, augmented by poetic inquiry and quantitative measurements, were used to discover factors that inhibited or enhanced five mothers' recognitions. These factors were then evaluated using a frequency distribution analysis and a rank-order correlation. The phenomenon of recognition was, for these mothers, a process of *waiting to hear that "normal" had stopped*, wherein they miscategorized symptoms as normal behaviors in a passing developmental phase. Prior experience with mental illness appeared to significantly decrease both the length of time and the level of distress necessary for recognition. Ultimately, recognition did not occur until someone in their social network validated their concerns and provided explicit confirmation, which galvanized them to seek treatment. Governance network collaborations can facilitate positive social change by standardizing guidance on how to differentiate symptoms of a disorder from normal childhood development. Public policies and programs such as universal mental health screening, mental health literacy, and more supportive and responsive school policies can foster dialogue for parental recognition in Colorado and throughout the country.

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Dedication

To my parents – Daniel and Joan Aceto – who modelled the value of education, family, and a sense of humor.

To my children – Bram, Ramona, Jeremy, and Elena Salgado – who endured so many frozen dinners, hugged me almost every night, and graciously permitted me to graduate before they did.

To my husband – Paul Salgado – who for 30 years (and counting) enriches my life every day, and rarely complained about washing the dishes. This is the second time you’ve helped me earn my wings.

Acknowledgments

Each of us has cause to think with deep gratitude
of those who have lighted the flame within us.
~ Albert Schweitzer

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Most importantly, my brilliant and inspiring chairperson, Dr. Steven A. Matarelli. For more than 100 weeks, your mentoring and example truly sparked the flame within me. No matter what obstacles arose, you never failed to rekindle my enthusiasm, and ignite my aspirations for social change—Onward!

I hope to prove worthy of your trust, and keep the flame alive.

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Chapter 1: Introduction to the Study

Recognition of Childhood Mental Illness

Her parents
she said
    Put a pinball machine inside her head
when she was five years old. . . . .

The red balls tell her: She should laugh!
The blue balls tell her: She should be silent . . . .
    (and Keep away from other people!)
The green balls tell her: She should start multiplying by three   (by 3   by 3   by 3!)

Every few days
she said
    a silver ball ricochets through the pins in her brain. . . .

I asked her
    What does the silver ball mean?

Her eyes went vacant . . . . . then lifeless. . .
        and I never found out what the silver ball meant. . . . .

(Found poetry inspired by *An Unquiet Mind: A Memoir of Moods and Madness* [Jamison, 1997])

Childhood mental illness is pervasive, with an estimated 15 million children in the United States suffering from a diagnosable mental illness (American Psychological Association [APA], 2014). Despite mounting evidence that early identification and treatment can benefit both a child’s long-term prognosis and their quality of life (Jorm, 2012), only a fraction of the millions of children in need actually receive professional treatment (Herman et al., 2011). Thus childhood mental illness is emerging as a public health crisis, costing taxpayers nearly $247 billion annually (Blau, Huang, & Mallery, 2010).

Background

When a child is sick, a parent’s instinct is to care for them. Unfortunately, the paradox inherent in mental illness is that the majority of parents do not recognize the symptoms as a medical condition requiring treatment (Boulter & Rickwood, 2013). While parents are typically aware that their child’s behaviors may be unusual when compared to peers, they do not define the problem as related to a mental illness that could benefit from diagnosis and treatment. Yet children are not immune to mental illness, and many disorders manifest in childhood. The Surgeon General estimates that approximately 20% of children suffer from a mental disorder (U.S. Department of Health and Human Services [HHS], 1999), but fewer than one-fifth of these children ever see a professional (Herman et al., 2011).

To understand why the majority of children in need are not receiving treatment, I investigated a variety of models that explain the help-seeking process. Beginning with general theories about medical help-seeking, models evolved that addressed the specific process of seeking treatment for mental illnesses. Although the majority of the existing models were based on adults seeking help for their own mental illness, in recent years a few theorists have sought to understand the process of parental help-seeking for their child’s mental illness (Boulter & Rickwood, 2013; Murry, Heflinger, Suiter, & Brody, 2011). The importance of recognition is a common thread within the preponderance of help-seeking models (Boydell, Volpe, Gladstone, Stasiulis, & Addington, 2013; Wilson, Bushnell, & Caputi, 2011), and although there are a variety of obstacles that can impede the help-seeking process, lack of parental recognition of mental illness is typically an overriding barrier to obtaining treatment (Sayal et al., 2010b). Therefore, this study focused on understanding this pivotal initial process—parental recognition of their child's mental illness.

Problem Statement

Current policies and programs for mental health service delivery are not sufficiently responsive to the early help-seeking dynamics of children and their families (Blau et al., 2010; Jensen et al., 2011; Keeton, Soleimanpour, & Brindis, 2012). Public schools have become the *de facto* system of mental health care for children (Gall, Pagano, Desmond, Perrin, & Murphy, 2000), and thus the focus for care is typically on providing services after a diagnosis rather than on helping families recognize the initial need for treatment (Colorado Association for School-Based Health Care [CASBHC], 2011b; Heller, 2014). One example of a public policy program that shifts the focus of care towards prevention and early identification is the school-based health center (SBHC) model (Keeton et al., 2012). The state of Colorado has invested in SBHCs for over 30 years, and research has been conducted on their efficacy from the standpoint of policy makers, adolescents, school personnel, and health providers. However, few studies have examined the use of SBHCs from the parent's perspective (O'Leary et al., 2013), which is a significant gap, since parents are responsible for making medical treatment decisions for their children.

In the literature on help-seeking for mental illness, the majority of studies have focused on individuals who were seeking treatment for their own disorders, and most frequently the participants were adults or sometimes adolescents (Flink, Beirens, Butte, &

Raat, 2014). Several studies have examined the process of parents seeking care for their mentally ill children (Arcia & Fernandez, 2003; Boulter & Rickwood, 2013; Logan & King, 2001), and the topic of recognition has assumed increasing importance (Bevaart et al., 2012; Reavley & Jorm, 2011). However, despite the call for more research on the early steps of the help-seeking process (Crowe et al., 2011; Thomson et al., 2012), only a few studies have honed in on the initial step of recognition, and fewer still have examined the impact of existing policies and programs on parental recognition. My hope for this study was to augment the evolving understanding of the intersection between public policy and treatment seeking for childhood mental illness by focusing on the essential first step of parental recognition.

Purpose

This concurrent mixed methods study explored the process of how parents and caregivers in the Pikes Peak Region of Colorado learned to recognize their child’s behaviors as resulting from mental illness, and how school-based health centers affected their recognition process and initial decision to seek treatment. I used in-depth qualitative interviews and elements of poetic inquiry to understand the meaning inherent in this process, while concurrently employing quantitative surveys and scales to complement and triangulate responses, and to measure the relationship between the presence of a school-based health center (SBHC) and parents’ recognition of their child’s mental illness. Combining qualitative and quantitative methods facilitated a deeper and broader understanding of the effect of these public policy decisions upon parents’ abilities to recognize their child’s mental illness. This understanding can help guide the development of treatment programs for this at-risk population, and hopefully begin to mitigate the emerging public health crisis in childhood mental illness (Blau et al., 2010; Bruns et al., 2014; McCabe, Wertlieb, & Saywitz, 2013).

Nature of the Study

Capturing the complexities of human behavior can be enhanced by triangulation of a variety of inductive and deductive approaches (Denzin, 2012). To capitalize on both the richness inherent in language and the patterns revealed by numbers, I relied on a convergent parallel design for this study (Creswell & Plano Clark, 2011). The qualitative phenomenological strand predominated my research, and was enriched by use of a quantitative cross-sectional strand during the data collection, analysis, and reporting phases. The research design was rooted in the theoretical model of transcendental phenomenology offered by Moustakas (1994), and enhanced by incorporating elements of poetic inquiry (McCullis, 2013; Prendergast, 2009) into the phenomenological approach. During in-depth interviews with Colorado parents who have experienced the study phenomenon, I integrated quantitative cross-sectional survey and multi-variate data analysis to enable triangulation (Creswell & Plano Clark, 2011) while exploring the research questions.

Research Questions and Hypotheses

The two main research questions queried: How do parents describe their experiences of recognizing that their child’s behaviors are related to a mental illness that requires treatment? To what extent does the presence of a school-based health center in the community affect parental recognition and initial treatment decisions? Other related sub-questions that emerged as a result of delving into the main research questions included:

1. Qualitative research subquestions.
    a) What impedes or enhances parents' perception and initial treatment decisions?
    b) How and why do parents overcome barriers to problem recognition?
2. A quantitative research subquestion.
    a) Which factors will significantly contribute to the percent variance change accounted for in parental problem recognition?

For the quantitative component, I used the following hypotheses to examine the relationship between the independent variables of (a) normalization, (b) explanatory models, (c) stoicism, (d) stigma, (e) previous experience with mental illness, (f) social network, (g) media, (h) distress, (i) crisis, and (j) presence of a SBHC and parental problem recognition:

> $H1_O$: The independent variables of (a) normalization, (b) explanatory models, (c) stoicism, (d) stigma, (e) previous experience with mental illness, (f) social network, (g) media, (h) distress, (i) crisis, and (j) presence of a SBHC will not significantly contribute to the percent variance change accounted for in parental problem recognition of their child's mental illness.
>
> $H1_A$: The independent variables of (a) normalization, (b) explanatory models, (c) stoicism, (d) stigma, (e) previous experience with mental illness, (f) social network, (g) media, (h) distress, (i) crisis, and (j) presence of a SBHC will

significantly contribute to the percent variance change accounted for in parental problem recognition of their child's mental illness.

Theoretical Foundation and Conceptual Framework

Firmly rooted in public policy, this study supported the goals of the President's New Freedom Commission on Mental Health (PNFCMH) which articulated a vision for "a future when mental illnesses are detected early, and a future when everyone with a mental illness at any stage of life has access to effective treatment and supports" (PNFCMH, 2003, p. 1). In the decade since this vision was first published, national goals and objectives have been implemented to improve childhood mental health and family empowerment through educational and community-based programs, with a growing emphasis on emerging issues in early and middle childhood (HHS, 2014), and the importance of including families (Centers for Disease Control and Prevention [CDC], 2014). Additionally, the Patient Protection and Affordable Care Act (ACA) includes grant funding to support SBHCs (Colorado Health Institute, n.d.). Despite these advances, the near exclusion of *mental* health literacy in our national action plan to improve overall health literacy (HHS, Office of Disease Prevention and Health Promotion, 2010b; Mendenhall & Frauenholtz, 2013) underscores the need for improvement in our public policies, since mental health is a pivotal component of overall wellness (PNFCMH, 2003).

These recent changes in policy, the health care system, and the theoretical literature provide opportunities to extend theory and improve practice. In order to do so, I developed a framework for this study which relied on a constructivist paradigm

(Creswell, 2013), and drew upon several recent and emerging theories and concepts. Specifically, I used Logan and King's (2001) model of parent-mediated pathways to mental health services for adolescents, Jorm's (2012) concept of mental health literacy, and Rhodes' (1996) articulation of the interdependent relationship of public, private, and non-profit exchanges articulated in his governance network theory. This section offers an overview of these theories and concepts which are more thoroughly discussed in the next chapter.

The concept of pathways to care—help-seeking processes that are shaped by culture and context (Cauce et al., 2002)—has influenced empirical studies for over two decades. I derived the model of parent-mediated pathways to mental health services for adolescents from classic help-seeking models (Logan & King, 2001), and then augmented this understanding with elements of the Transtheoretical Model/Stages of Change Theory (Prochaska, Redding, & Evers, 2008). Next, I used the concept of mental health literacy to extend the treatment-seeking dialogue into the public policy arena by linking it to our national health policy goals (Jorm, 2012; PNFCMH, 2003), thus providing a firm basis for both this dissertation research and subsequent social change. Finally, I used the theory of governance networks to better understand how self-organizing and inter-organizational networks are emerging as important means of public service production and delivery in our fragmented and decentralized political system (Sørensen & Torfing, 2005). Many of the current policy debates most germane to children's mental health and parental recognition emphasize the need for collaboration and partnerships in order to serve families and communities affected by childhood mental illness.

School-based health centers (SBHCs) are an example of a network that shares boundaries between the public policy domains of health and education, and also between government, corporate, and non-profit entities. Thus SBHCs in Colorado served as the nexus from which to examine the intersection of these three theories and perspectives, and to more fully understand the process of parental recognition of their child's mental illness.

Definitions

Child: A person under the age of 18 (U. S. Census Bureau, 2013). For the purposes of this study, unless it becomes necessary to differentiate between age groups, there will not be a distinction between a child and an adolescent or teen.

Crisis: A breaking point reached as the result of extreme distress.

Diagnosis: An assessment of a mental disorder made by a qualified mental health, substance abuse, or medical professional (Substance Abuse and Mental Health Services Administration [SAMHSA], 2011).

Distress: An accumulation of a seemingly insurmountable level of burden to the parents or the family (Oldershaw, Richards, Simic, & Schmidt, 2008).

Explanatory model: How a parent explains the origins of their child's behaviors, including their beliefs about the etiology or causes of the illness, the meaning of symptoms, the course of treatment, and the expectations of affected individuals (Jacob, 2010).

Help-seeking: “In the mental health context, help-seeking is an adaptive coping process that is the attempt to obtain external assistance to deal with a mental health concern” (Rickwood & Thomas, 2012, p. 180).

Media: Publicly available information sources such as books, television, and the internet.

Mental disorder: “[A] syndrome characterized by clinically significant disturbance in an individual’s cognition, emotion regulation, or behavior that reflects a dysfunction in the psychological, biological, or developmental processes underlying mental functioning. Mental disorders are usually associated with significant distress or disability in social, occupational, or other important activities” (American Psychiatric Association, 2013, para. 2). Additionally, mental disorders in children involve “serious deviations from expected cognitive, social, and emotional development” (HHS, 1999, p. 123).

Mental health literacy: The “knowledge and beliefs about mental disorders which aid their recognition, management or prevention” (Jorm, 2012, p. 231). This concept encompasses the knowledge, beliefs, and attitudes about mental illness and help-seeking (Jorm, 2012), and also emphasizes that the ability to recognize mental illness is the progenitor of treatment seeking (Jorm, 2012; Mendenhall, 2012).

Mental illness: The “term that refers collectively to all diagnosable mental disorders” (HHS, 1999, p. 5).

Normalization: When an individual redefines abnormal or dysfunctional symptoms as within the range of typical, everyday distress (Biddle, Donovan, Sharp, &

Gunnell, 2007), or minimizes the negative effects of the problems (Saunders & Bowersox, 2007).

Parent: The adult caregiver responsible for making medical treatment decisions for the child. This person may not be the child's biological mother or father, but may be a grandparent, step-parent, adoptive parent, or guardian (U. S. Census Bureau, 2013). Throughout this paper, the use of the term *parent* will predominate, and the intent is that it be used inclusively to indicate both parents and other adult caregivers of children.

Previous experience with mental illness: The experience of dealing with a mental illness in oneself or a significant other, such as a family member or close friend.

Problem recognition: For this research, problem recognition is considered to be a precursor to treatment seeking for mental illness, so the definition developed for this study combines the cognitive elements emphasized by Mechanic (1982, as cited by Logan & King, 2001) with the process orientation of help-seeking by Rickwood and Thomas (2012) and the socio-behavioral aspects offered by Cornally and McCarthy (2011). Thus problem recognition will be defined as a coping process involving a decision about the causation and abnormality of symptoms, resulting in an interaction with a mental health-care professional.

School-based health center (SBHC): A health service facility operated by a school district in cooperation with public or private health care organizations (Colorado Department of Public Health and Environment, 2009), in order "to provide integrated physical and behavioral health services to students" (Colorado Association for School-Based Health Care, 2011b, p. 1).

Social networks: Social relations between “bounded sets of actors…that are connected by specific relationships” (Schmidt, 2007).

Stigma: A negative reaction or response from a social network, which stems from assumptions about differences or inferiority (Gerrig & Zimbardo, 2002).

Stoicism: Attitudes that convey self-management and the ability to solve one’s own problems (Thompson, Hunt, & Issakidis, 2004).

Scope

I initially advertised this study in twelve school districts in three Colorado district regions—the Metro, Pikes Peak, and Northwest Regions—based on a prevalence of SBHCs within each district. Eligible participants must have been the caregiver responsible for making medical treatment decisions for a child who had received an evaluation or diagnosis of a psychological disorder within the past year.

Assumptions

Several assumptions underscored this research. The overriding assumption was that if their child has received a diagnosis, then the parent/caregiver had gone through the process of recognizing the child’s mental illness. Next, the selection of a mixed methods approach was based on the assumption that the integration of methodologies would be complementary, and would synergistically generate more useful evidence than either quantitative or qualitative methods would if used independently. Finally, my use of interviews as the primary data collection tool was based on the assumption that the participants would be telling the truth as they remembered it.

Limitations

Data gathered through interviews can be distorted by bias, lack of awareness, or emotions (Patton, 2002). Also, since participants were recounting experiences from their past, they may forget information, or purposely misconstrue events for self-serving purposes, a tendency known as recall error (Patton, 2002). Another possible distortion could occur due to the perceived influence of the interviewer (Patton, 2002), or to participants' responses to the interviewer's race, gender, or ethnicity. Further, the researcher's personal experience with the research phenomenon could bias their collection, analysis, and interpretation of the data. I discuss this particular limitation in detail in subsequent chapters.

A potential limitation existed for gender homogeneity among participants. The literature consistently reports that mothers are the most likely caregiver to seek treatment for their children (Boulter & Rickwood, 2013), so there may have been a paucity of fathers who volunteered for this study.

My decision to not restrict the type of diagnoses to a particular set of mental illnesses might also limit the usefulness of the results. Potentially examining a very broad collection of mental illness diagnoses can obfuscate patterns in the data.

Delimitations

The delimitations that are present resulted from decisions I made regarding population and sample. Since the locations for Colorado SBHCs are made with the concept of a medical safety net in mind (Colorado Association for School-Based Health Care [CASBHC], 2011b), the demographic characteristics of the participants in these regions—particularly the economic brackets—may restrict generalizability or transferability to other populations throughout the state. Further, since SBHCs are located in neighborhoods that are predominantly Hispanic, I anticipated that many of the potential participants would have insufficient fluency with English.

Significance and Implications for Social Change

In the United States, mental illness is the leading cause of disability, with an economic burden that stretches into future generations (Wilson et al., 2011). Since many chronic mental disorders manifest in childhood and benefit from early and sustained treatment (Berk et al., 2010; Thomson et al., 2012), childhood diagnosis and care are significant factors in reducing the negative impacts to these communities, families, and individuals (Jorm, 2012; PNFCMH, 2003). Mental health underscores many societal issues such as homelessness, school dropout rates, child abuse and neglect, foster care, and prison overpopulation (Stagman & Cooper, 2010), so the results of this study can have wide applications for social change, specifically on issues related to inequality and disability-related discrimination (Burns, 2009). Further, since programs that promote children’s mental health have shown to provide a five-fold return on investment within five years (McDaid, 2011), policy makers and practitioners in the fields of public health (Sayal, 2006), psychiatry, law enforcement, education (Mills et al., 2006), and social work (Mendenhall & Frauenholtz, 2013), can utilize the results of this study as they seek to improve the health and effectiveness of communities and the lives of children and families through early detection and treatment.

Recognition is likely to result in treatment, and so an improved understanding of the recognition process could help policy makers replace reactive policies and programs with more proactive ones. One example of positive social change would be a complete paradigm shift in the response to symptoms of mental illness. For example, the current system criminalizes many behaviors of unrecognized mental illness, so redirecting resources from the legal and prison systems to the education and public health systems could break this cycle, and result in increased treatment. Several initiatives such as school-based health centers (U.S. Department of Health and Human Services [HHS], 2011; Walter et al., 2011), mandatory screening for childhood mental illness (Kennedy, 2014; PNFCMH, 2003), and the Mental Health in Schools Act of 2013 (Bazelon Center, 2014) facilitate early recognition and treatment for childhood mental illness, and reallocating funds to these types of programs could not only improve wellness at the individual level, but also productivity at the community level, as children receive treatment that will enable them to avoid the criminal justice system and become healthy, prosperous adults. This research can contribute to an enhanced understanding that may facilitate treatment for millions of children and families in need.

Summary

Ethical public administrators make policy decisions in the public interest (Woller, 1998), in order to improve communities and the lives of their residents. In response to the emerging public health crisis of childhood mental illness, public officials have enacted, and are considering, a variety of policy options. This study involved Colorado’s public policy decision to invest in SBHCs by examining the effects of these facilities on parents’ recognition of their children’s mental illness. By investigating how parents in the Pikes Peak Region of Colorado learned to recognize their child’s disorder, and how school-based health centers affected their recognition process, this study can contribute to positive social change by informing policy makers about whether SBHCs are being used in the fullest measure to advance national and state public health policy goals.

This chapter served as an introduction to the mixed-methods study and provided an overview of the background, purpose, and need for this research. In Chapter 2, I review relevant research literature on help-seeking for mental illness, parental recognition, and public policies that impact parental help-seeking, and I identify a gap in the scholarly literature. Chapter 3 details the methodology for this study, describing the interplay between the qualitative and quantitative strands, and how elements of poetic inquiry were used to enhance the research.

Chapter 2: Literature Review

Introduction

Recognition of childhood mental illness as a component of treatment seeking is a complex construct, with some theorists suggesting that it may be an entire process unto itself (Logan & King, 2001). Since the goal of this study was to understand parental recognition of their child's mental illness as a precursor to obtaining treatment, I examined the phenomenon within the context of the help-seeking process. Therefore, after outlining the literature search strategy and theoretical and conceptual foundation, this literature review will follow three major trajectories, organized by section. In the first section, I frame the concept with an overview of various help-seeking and pathways to care models, and focus specifically on literature dealing with recognition of and treatment for mental illness. In the second section I focus on parental help-seeking, and highlight a variety of factors and themes that have been studied in relation to this process. These factors then lead to an examination, in the third section, of a specific public policy decision which may have an impact on parental recognition—the presence of a school-based health center (SBHC) in the community. Following the literature review, I discuss the methodology and provide justification for its selection. .

Literature Search Strategy

In order to thoroughly understand this complex phenomenon, I structured the literature search into four distinct segments: scholarly studies since 2010 on parental recognition; historical foundations of help-seeking (since the 1950s); recent public policies and programs that deal with childhood mental illness; and a survey of popular literature, poetry, and songs on the subject of mental illness. I gleaned most of the current and historical scholarly literature through a search of multiple databases in the Walden University online library, using general databases such as Academic Search Complete, Educational Resource Information Center (ERIC), ProQuest Central, SAGE Premier, and Thoreau, and specialized databases including MEDLINE, Political Science Complete, PsychINFO, and Soc INDEX. Additionally, searches using Google Scholar identified leads from the reference sections of other scholarly articles. Additional material was obtained by searching directly within publications, such as the *Community Mental Health Journal* and the *Journal of Social Issues*.

To enhance my knowledge of recent public policies and programs, I extended beyond scholarly databases to a variety of websites sponsored by government and non-profit agencies including Colorado Mental Health, Colorado Department of Education, the National Alliance for the Mentally Ill (NAMI), the Substance Abuse and Mental Health Services Administration (SAMHSA), and the U.S. Department of Health and Human Services (HHS). Finally, to facilitate use of poetic inquiry as a component of the methodology for this study, I used search engines from Google, the Pikes Peak Library District, and various non-profit libraries such as those sponsored by the Depression and Bipolar Support Alliance (DBSA) of Colorado Springs to obtain poems, lyrics, and other popular literature that could be used to create found poetry. Keywords for all search methods included terms and permutations such as *mental illness, disorder, recognition, awareness, perception, understanding, schema, help-seeking, non-help-seeking, treatment, health, pathways, policies, services, mental health literacy, parent, child,* *adolescent, behavior, delay, normalization, medical sociology, screening, schools, public health,* and *community.*

Theoretical and Conceptual Base

Classifying the recognition of a child’s mental illness as a distinct process is a relatively new idea. I therefore grounded this study in theories and concepts based on a variety of viewpoints. By using three different perspectives to anchor this study—the model of parent-mediated pathways to mental health services for adolescents (Logan & King, 2001), the concept of mental health literacy (Jorm, 2012), and the theory of governance network (Rhodes, 1996)—I gathered information that may be useful not only to scholars, but also to practitioners and policy makers as they seek to coordinate and improve mental health services for children and families. Before describing how I melded these perspectives in this research study, I explain each individually.

Model of Parent-Mediated Pathways to Mental Health Services for Adolescents

Since one of the desired outcomes of this study was to facilitate treatment for childhood mental illness, a help-seeking model was a valuable component of the theoretical and conceptual foundation. The model of parent-mediated pathways (PMP) was the most appropriate for this study because Logan and King (2001) isolated and expanded each step of the help-seeking process, and thus offered one of the few models to explicate the recognition or awareness phase of the process. Although the model is designed to represent help-seeking for adolescents, the process is contingent upon parent involvement and thus was relevant to this study of parental help-seeking for children of all ages.

An amalgam of components from several classic models and theories, the PMP model is rooted in the stages of change constructs from the transtheoretical model of health behavior which emphasizes both contemplative and action stages (Prochaska, Redding, & Evers, 2008). The PMP model uses these stages to align its six-phase progression into both cognitive and behavioral steps: (a) gaining awareness of an adolescent's distress, (b) recognizing the problem as psychological in nature, (c) considering possible courses of action, (d) developing an intention to seek mental health services, (e) making an active attempt to seek services, and (f) obtaining mental health services for/with the adolescent (Logan & King, 2001, p. 322). Surrounding this core sequence is a variety of environmental factors that influence the process, the most pertinent of which I will discuss in greater detail later in this chapter.

Scholars are finding value in the PMP model for their research. In a study of justice system-involved youth, Watson (2009) concluded that parental awareness of a problem, and their ability to recognize that problem as a mental illness, were two different events. Bevaart et al. (2012) examined ethnic differences in problem perception, and confirmed that problem perception should be a separate stage from recognition in the help-seeking process.

Mental Health Literacy

The concept of mental health literacy united the elements in this study, linking the understanding of parental perception with the need for salient policies and programs. It built upon the constructs of general health literacy, which is the ability to "obtain, process, and understand basic health information and services needed to make appropriate health decisions” (HHS, Office of Disease Prevention and Health Promotion, 2010b, p. 1). Although general health literacy has been a part of our national health objectives for nearly three decades (HHS, Office of Disease Prevention and Health Promotion, 2010a; HHS, Public Health Service, 1990), a similar emphasis on *mental* health literacy is noticeably absent from the current national health agenda (HHS, Office of Disease Prevention and Health Promotion, 2010b; Mendenhall & Frauenholtz, 2013), and thus is an area that needs far greater attention.

The term *mental health literacy* was introduced in the mid-1990s in order to emphasize the importance of educating the public about mental disorders (Jorm, 2012). Defined as “knowledge and beliefs about mental disorders which aid their recognition, management or prevention” (Jorm, 2012, p. 231), mental health literacy transcends mere knowledge about disorders, by translating comprehension into action that enhances individual or community mental health (Jorm, 2012). Mental health literacy involves several related components including prevention, recognition, help-seeking options and strategies, and first-aid care for mental disorders (Centre for Health Program Evaluation, 2002; Jorm, 2012; Reavley & Jorm, 2011). There is also a strong element of individual and community empowerment inherent in the concept of mental health literacy, enabling interventions from social networks, public agencies, and non-profit organizations (Jorm, 2012; Mendenhall & Frauenholtz, 2013).

Just as improvements in general health literacy result in enhanced public health outcomes, there are positive correlations between increased mental health literacy and the amount and quality of services used for mental illness (Coles & Coleman, 2010; Erritty &

Wydell, 2013; Henderson, Evans-Lacko, & Thornicroft, 2013; Rickwood, 2011), including childhood mental illness (Mendenhall & Frauenholtz, 2013; Wilson et al., 2011). Successful implementation of nationwide policies and campaigns in Britain (Sayal et al., 2010a) and Australia (Pierce & Brewer, 2012) have been shown to improve mental health literacy at both the individual and community levels, and underscore the importance of effective public policies and coordination on treatment-seeking and recognition.

Governance Network Theory

How communities view and respond to mental illness can impact a parent's ability to recognize and obtain treatment for their child's condition. Since public policy networks are emerging in the literature as particularly effective in responding to urgent and complicated social problems (Ferlie, Fitzgerald, McGivern, Dopson, & Bennett, 2011; Manna, 2010), the theory of governance networks provided a useful component for the conceptual framework of this study.

Governance networks function through negotiations between autonomous yet mutually dependent entities from public, private, and voluntary sectors (Sørensen & Torfing, 2005), with interdependency serving as the core sustaining factor between members (Klijn & Koppenjan, 2012). The various agencies involved in networks are bound by self-responsibility (Montenegro & Bulgacov, 2014), trust, information flow, innovation (Hartley, 2010), resource exchange (Rhodes, 1996), negotiation (Sørensen & Torfing, 2005), and cooperation (Provan & Kenis, 2007). This is in contrast to both traditional government hierarchies and market-based competition, and network governance has been touted as a third option in public policy mechanisms (Sørensen & Torfing, 2005).

Although initially observed to be self-organizing (Rhodes, 1996) and non-hierarchical (Hartley, 2010), Provan and Kenis (2007) described that networks have evolved along a spectrum of three forms: participant-governed, wherein all members participate and distribute power relatively equally; the lead organization model, where one agency assumes a central leadership position for the network; and the network administrative organization (NAO; Provan & Kenis, 2007), with a separate administrative entity established to manage the network. The model most common in health and human services—such as mental health—is the lead organization model, where the organization that provides the core services or key resources typically assumes the central leadership role for the network (Provan & Kenis, 2007). However, the determinant of network structure is based on four important contingencies between the members of the network: (a) the network size, (b) the level of trust between the participants, (c) the type of undertaking, and (d) the degree of goal consensus (Provan & Kenis, 2007).

Networks may be self-initiated by the member organizations (Provan & Kenis, 2007), or they may be mandated, chartered, or contracted (Hartley, 2010; Provan & Kenis, 2007), frequently by a public sector agency. While networks possess many advantages over market-based or hierarchical forms of governance, they are not a guaranteed solution for every social problem (Manna, 2010). They carry disadvantages such as difficulties in maintaining accountability for results (Manna, 2010; Rhodes, 1996; Sørensen & Torfing, 2005), loss of transparency to constituents (Sørensen & Torfing, 2005), and a potential for lack of consensus on mutual goals (Manna, 2010). Despite these potential drawbacks, networks are appearing more frequently in public governance. In their review of public policy literature, Ferlie et al. (2011) noted a distinctive shift in public service organizations transitioning from vertical hierarchical structures to horizontal networks. The researchers further noted that these networks were most effective in dealing with complicated problems that exceeded the capability of a single agency, such as mental health treatment and services.

In Colorado, SBHCs function as a form of network governance, using the lead organization model. Typically located in communities with the most vulnerable populations (CASBHC, 2011a), SBHCs serve as collaborative community endeavors involving partnerships between health service organizations, schools, non-profit organizations, and communities (Colorado Health Institute, n.d.; Gampetro, Wojciechowski, & Amer, 2012) in order to offer access to care for a spectrum of physical and mental health needs. More information on these SBHC partnerships is provided later in this chapter.

The Intersection of the Three Perspectives

In this study I wove together elements of each of these theories and perspectives in order to more fully understand how parents learn to recognize their child's mental illness, and how public policies, programs, and systems interact in this process to impact both recognition and subsequent help-seeking. The use of governance networks is being legitimized through calls from government task forces and proposed legislation. For example, the President's New Freedom Commission on Mental Health (PNFCMH, 2003) encourages schools to partner with mental health service providers to enhance mental health care for children. Expanding on this call to action, government agencies such as the Substance Abuse and Mental Health Services Administration (SAMHSA) offer guidance on forging collaborations and partnerships between child-serving organizations (SAMHSA, 2011) in order to foster treatment and education about mental illness. Proposed legislation such as the Mental Health in Schools Act of 2013 (Bazelon Center, 2014) ties funding to collaborative network governance arrangements between public, private, and nonprofit agencies. Thus the interplay between the three perspectives of governance network theory, mental health literacy, and the model of parent mediated pathways becomes more apparent, necessitating an in-depth review of the literature on help-seeking models, the factors most germane to recognition, and the current policies, programs, and systems that appear to have the most effect on parental recognition.

Background on Help-seeking Models for Mental Illness

Within the last century, at least three important transitions have occurred in our understanding of treatment-seeking behavior in general, and help-seeking for mental illness in specific. Perhaps the most significant change is the shift in the leading causes of death and disability—away from illnesses caused by infection and towards chronic, non-communicable diseases such as cardio-pulmonary conditions, diabetes, and mental disorders (Glanz, Rimer, & Viswanath, 2008; Rickwood & Thomas, 2012). Our interpretation of help-seeking models and public health policies have adjusted to correspond to this shift, and since the 1950s both have emphasized the importance of individuals making choices about their health (Pescosolido, 1992), as well as the impact of culture and environment upon personal decisions (Andersen, 1995; Boydell, Volpe, Gladstone, Stasiulis, & Addington, 2013).

Advancement has also occurred in our understanding and interpretation of mental health as a medical phenomenon. While debate still resonates on the appropriate level of “medicalization” (Bosk, 2013) for care of mental disorders, there is little disagreement that most mental disorders have a biological basis, and that medicines can be an effective component of treatment (Reavley & Jorm, 2011). Further, as our knowledge of the onset of mental illness improves, acknowledgement that many disorders manifest in childhood is becoming more widespread (Sayal et al., 2010a), along with the recognition of the importance and effectiveness of early diagnosis and treatment (Godoy & Carter, 2013; Post, Chang, & Frye, 2013). Given that depressive disorders are predicted to become one of the major causes of death by the year 2030 (Glanz et al., 2008), and that mental illness is now one of the leading causes of disability (Wilson et al., 2011), it becomes increasingly important to understand the process of seeking help for childhood mental illness.

A third evolution within the help-seeking literature on mental illness has been a branching out from a dominant focus on adults seeking care for their own illness (Saunders & Bowersox, 2007) toward a greater body of research on both adolescents seeking treatment for their disorder (Thomson, Marriott, Telford, Law, McLaughlin, & Sayal, 2012), and on parents seeking care for their child’s mental illness (Boulter & Rickwood, 2013; Murry, Heflinger, Suiter, & Brody, 2011). Although the distinctions are important, there remains a great deal of overlap in the processes, and elements from each of these categories of research on help-seeking—adults, adolescents, and parents—proved useful to this study.

As understanding of the help-seeking process for mental illness continues to be refined, more scholars have called for research on the earliest stages of the process, specifically recognition (Logan & King, 2001; Reavley & Jorm, 2011) of a mental illness. Thus, there has been a variation in the number of studies that concentrated on later stages of the help-seeking models, which often focused on logistical barriers to treatment after recognition had occurred (Farmer, Farrand, & O'Mahen, 2012). In the most recent years there has been an increase in the number of studies that investigated and attempted to refine the stages of recognition and the initial help-seeking decision (Crowe, Inder, Joyce, Luty, Moor, & Carter, 2011; Zwaanswijk, Verhaak, Bensing, Van Der Ende, & Verhulst, 2003).

Finally, the connections between theory, research, and policy-making appear to be strengthening, especially with the application of concepts such as mental health literacy (Jorm, 2012). More scholars are examining the effects of policies and programs based on improving education, mental health, and mental health literacy (Gulliver, Griffiths, & Christensen, 2010; Pierce & Brewer, 2012),

Despite these progressions in help-seeking research, many gaps in the collective understanding remain to be filled. Perhaps most disconcerting is the lack of consensus on the definition of and conceptual framework for help-seeking (Rickwood & Thomas, 2012). Another prominent gap—and where the results of this study would be most useful—is the need for refinement and a greater understanding of the preliminary stages of help-seeking, specifically awareness, recognition, and the initial decision to seek treatment. Those agencies and professionals seeking to help children and families in need of care will benefit from understanding how, when, and why parents do—or do not—recognize the need for treatment for their child. In order to more fully explore these preliminary stages, first the most prominent types of help-seeking models will be detailed, and then recent research on the process of recognition as a component of the help-seeking process will be presented.

Overview of the Progression of Help-Seeking Models

Despite being a topic of research for over 50 years, as yet there is no common definition either for general help-seeking (Cornally & McCarthy, 2011) or help-seeking for mental illness (Rickwood & Thomas, 2012), nor is there an agreed-upon model or measurement for comparison of studies (Rickwood & Thomas, 2012). With this as an underlying caveat, nearly all of the help-seeking models for mental illness have at their core a series of steps, stages, or levels that progress in either a linear or a recursive fashion. Interestingly, permutations of only three basic steps provide an organizing framework for the majority of stage models—(a) problem definition, (b) decision to seek help, and (c) selection of service (Cauce et al., 2002). Evolving from this foundation of stages, help-seeking models for mental illness generally branch into two categories based on their theoretical foundations—those that emphasize rational or cognitive processes, and those that accentuate social-behavioral factors. More recently, help-seeking models have been placing increased emphasis on the importance of recognition (Bevaart et al., 2012; Godoy & Carter, 2013). Therefore, this discussion of help-seeking models will be organized around the three themes of cognitive models, social-behavioral models, and the importance of recognition across models.

Cognitive models and their progression. Viewing help-seeking as a decision, and thus as predominantly a rational, cognitive process, these models are grounded in constructs from rational-choice approaches or the theory of reasoned action. Rational-choice logic centers on individual decisions—typically deductive—made as a result of comparing their personal beliefs and perceptions about the likely consequences of their behaviors (Pescosolido, 1992). In similar fashion, the theory of reasoned action (TRA) involves cognitive processes such as attitudes and intentions, and their effect on behaviors (Montaño & Kasprzyk, 2008). However, unlike rational-choice approaches which divorce the individual from the effects of their society, TRA also incorporates the influence of social norms upon behavior and decisions (Ajzen & Fishbein, 1973; Montaño & Kasprzyk, 2008). In a review of the research literature by Ajzen and Fishbein (1973), a person's attitude about a specific behavior, coupled with their intention to comply with the expectations of their social group, was found to comprise the best predictor of subsequent action. This trend of acknowledging and incorporating social factors into cognitive models has become common in more recent models of help-seeking.

Building upon a rational-choice framework, Saunders and Bowersox (2007) offered an excellent example of a model that expands upon the basic organizing framework of stage models. Their seven-step model presents the largely individual cognitive actions of (a) recognizing a problem, (b) determining the problem is related to mental health, (c) deciding to change, (d) engaging in self-help efforts, (e) concluding that professional help is required, (f) deciding to seek professional help, and (g) seeking professional care for a mental health problem (Saunders & Bowersox, 2007). Although this model favors individual actions, it does consider the influence of an individual's social network upon their treatment-seeking decisions (Saunders & Bowersox, 2007).

When constructing the information-processing model of help-seeking, Vogel, Wester, Larson, and Wade (2006) combined cognitive steps with affective or emotional perceptions. Their four-step model is developmental, in that not everyone will experience all steps in the exact order, but most will begin at one point and move to the next (Vogel et al., 2006). For each of the four steps—(a) encoding and interpreting, (b) generating options, (c) decision making, and (d) evaluation of behavior—the authors offered implications for practitioners and policy makers, along with potential barriers to completing the stage (Vogel et al., 2006), and a discussion of factors related to recognition of mental illness is embedded in the first step of *encoding and interpreting* (Vogel et al., 2006). Hammer and Vogel (2013) subsequently expanded this and other cognitively-focused models to include more emphasis on social influences. Using structural equation modeling, it was noted that spontaneous, reactive decision-making accounted for significant variance in help-seeking decisions over deliberate reasoning processes among college students (Hammer & Vogel, 2013).

One model that specifically deals with parental help-seeking for their child's mental illness is known as the "level and filters model" (Bevaart et al., 2012, p. 1063). In order to progress to the next level of service use, the parent must negotiate and pass through a perceptual or cognitive filter (Zwaanswijk et al., 2003). For example, to move from awareness that something is wrong (level 1) to consulting a general practitioner (level 2), the parent must progress through the first filter, involving their recognition of the behavior and decision to consult a physician (Sayal, 2006). The second filter of this model also deals with perception and recognition, although this time it is the physician that must recognize mental illness in order to enable the parent to proceed to the next level. While this model contains some applicable elements, its emphasis on a specific track through the multiple medical stages commonly found in the Netherlands and Great Britain (Zwaanswijk et al., 2003) limited its usefulness to this study. However, it has inspired other scholars to develop subsequent models that will have greater applicability for this research, and which will be discussed later in this chapter.

Godoy and Carter (2013) extended this construct of the need for recognition by both the parent and the physician in order to secure treatment, and the authors highlight the motivational factors and sociocultural factors that can influence the cognitive process of recognition. Sociocultural factors shape the education, beliefs, and expectations of parents and physicians, and thus contribute to the explanatory models that both use to interpret behavior (Godoy & Carter, 2013). Motivational factors such as willingness and readiness to change their actions were cited as pivotal to taking actions towards help-seeking (Godoy & Carter, 2013). Willingness to change, aided by a blend of socio-cognitive factors, also emerged as key elements of the prototype/willingness model (PWM; Hammer & Vogel, 2013). In the PWM, willingness is affected by “situational and social influences on behavior” (Hammer & Vogel, 2013, p. 84), and has been shown to be more predictive of behaviors that are perceived as unfamiliar, socially undesirable, or emotional (Hammer & Vogel, 2013).

Social-behavioral models and their progression. While recent cognitively based models are emphasizing the interplay of social factors with the help-seeking process, social-behavioral models have embraced the embedded nature of culture and behavior for decades. One of the earliest proponents of this perspective developed a behavioral model of help-seeking which included forces that enabled or inhibited use of services (Andersen, 1995). These forces included predisposing characteristics such as age and gender, enabling factors such as situational variables and resources, and need variables such as the perceived need for care (Andersen, 1995; Logan & King, 2001; Mendenhall, 2012). Murry et al. (2011) augmented this perspective by including cultural and contextual barriers such as stigma and preferences for informal supports.

Another pre-eminent approach was Mechanic's (1995) study of illness behavior, which laid the groundwork for the illness career perspective (Watson, Kelly, & Vidalon, 2009). Illness behavior theories examined the different ways that people responded to, defined, and interpreted symptoms, what initial actions were taken, and how they utilized formal and informal care resources (Mechanic, 1995). The illness career perspective incorporated these constructs into a five-stage model involving (a) recognition, (b) decision to obtain professional care, (c) following medical advice, (d) assessment of treatment outcome, and (e) long-term compliance with care (Watson et al., 2009). This model is not linear, but dynamic—stages may not occur in order, or may be skipped or repeated (Watson et al., 2009).

Evolving from the illness career paradigm, Pescosolido (2010) depicted the response to illness as a social process that relied on a variety of networks. Known as the network-episode model (NEM), it focused on the importance of formal and informal social networks as the primary mechanism for recognition of and response to mental illness (Pescosolido, 2010). More recently, the revised network episode model has been developed specifically for children and adolescents, and prominently features the community school system as a social support network (Boydell et al., 2013).

Non-help-seeking and delay. Examining illness behavior from a contrasting perspective, some scholars contended that since seeking care for any condition is the exception rather than the norm (Moffat, 2010), the process of delay would therefore be worthy of study. Thus the question shifts from why people delay treatment, to why people make the decision to *stop* delaying (Zola, 1973). Five triggers were proposed, which could be clustered into characteristic decision-making patterns: (a) an interpersonal crisis, (b) perceived interference with social activities or relationships, (c) sanctioning by some part of the social network, (d) perceived impact to physical or vocational activities, and (e) the act of temporalizing or setting time limits on the symptoms (Moffat, 2010; Zola, 1973). More recently, Biddle, Donovan, Sharp, and Gunnell (2007) presented a model of non-help-seeking known as the cycle of avoidance, which featured a polarized continuum of distress with a constantly shifting threshold as the person seeks to make meaning of the symptoms of mental illness (Figure 1). Crossing the threshold to treatment is typically precipitated by some sort of crisis event (Biddle et al., 2007).

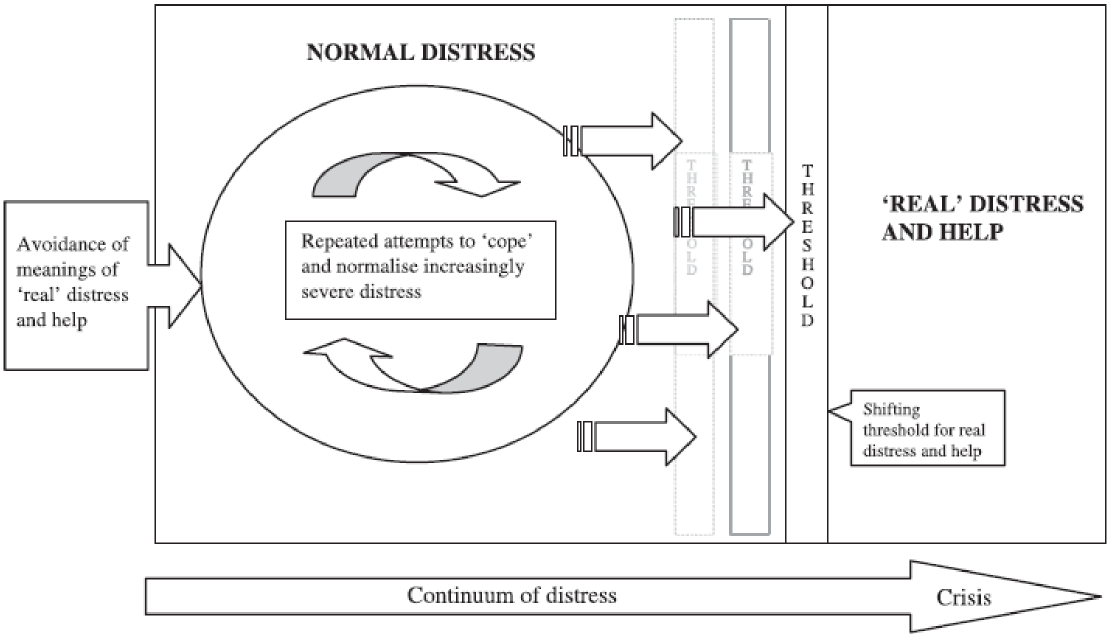

Figure 1. The cycle of avoidance. From "Explaining non-help-seeking amongst young adults with mental distress: A dynamic interpretive model of illness behavior," by L. Biddle, J. Donovan, D. Sharp, and D. Gunnell, (2007), *Sociology of Health & Illness, 29*(7), p. 988. Copyright 2007 by the Foundation for the Sociology of Health & Illness/Blackwell Publishing Ltd. Reprinted with permission (Appendix A).

The importance of recognition. Although a distinction has been drawn between socio-cognitive models and social-behavioral models for the purpose of discussion, the disparity is not pronounced, and is based more on the theoretical evolution of each model rather than a rigid delineation. In both theory and practice, scholars acknowledge the blending of cognitive, affective, and social elements as precursors to help-seeking behaviors, and recent models strive to combine the rich tradition of knowledge that is available on the topic of help seeking, and apply that to the growing understanding of help-seeking for childhood mental illness.

Therefore, for this study, the model of parent-mediated pathways (PMP; Logan & King, 2001) was the most apropos, not only since it melded these significant elements together, but also because it divided the process of parental help seeking into two separate stages of contemplation and action (Figure 2). This is important since a common thread that connects nearly all of the models is the importance of recognition, and scholars are beginning to call for research that explicates this segment of the help-seeking process (Crowe et al., 2011; Thomson et al., 2012; Zwaanswijk et al., 2003).

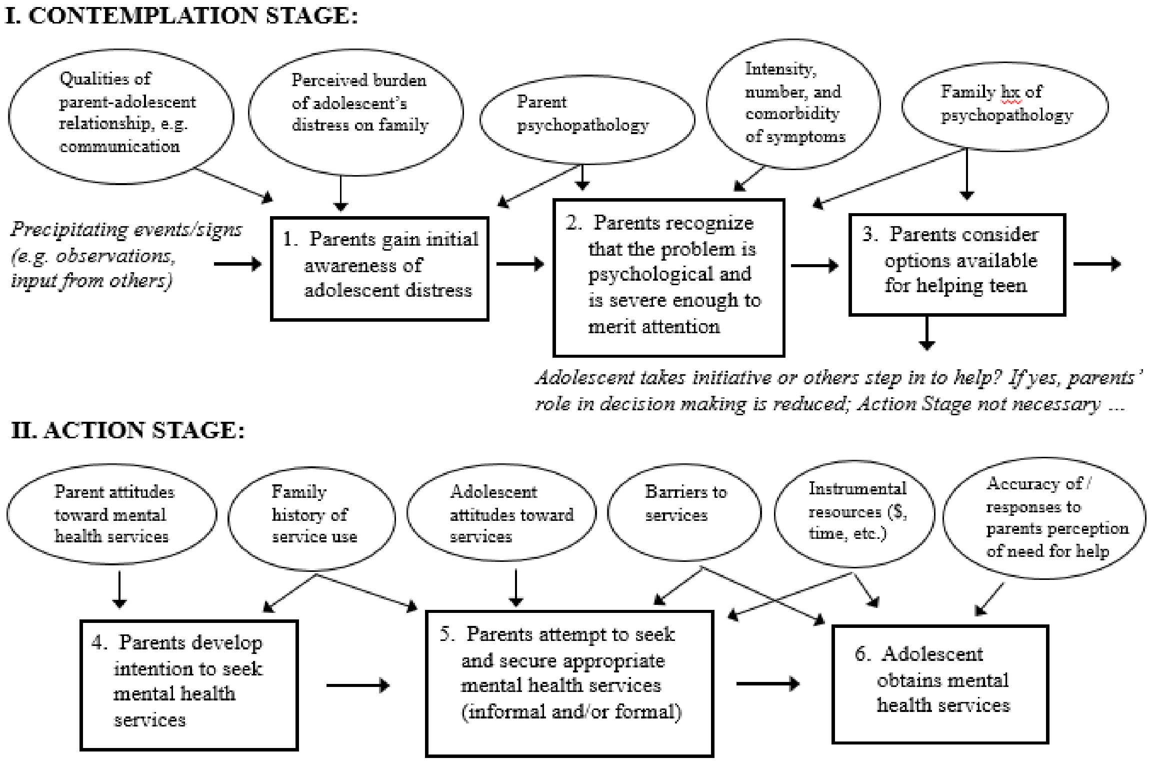

Figure 2. Parent-mediated pathway to mental health services for adolescents. From "Parental facilitation of adolescent mental health service utilization: A conceptual and empirical review," by D. E. Logan, and C. A. King (2001), *Clinical Psychology: Science and Practice, 8*(3), p. 322. Copyright 2001 by The American Psychological Association. Reprinted with permission (Appendix B).

Problem recognition was typically acknowledged not only as the pivotal and foundational aspect of the treatment-seeking process for childhood mental illness (Boydell et al., 2013; Wilson et al., 2011), but also as "universally important" (Sayal, 2006, p. 651) regardless of differences in international health policies and systems. For example, in their study of urban Canadian youth at ultra-high risk for psychosis, Boydell et al. (2013) used a multiple-case study approach to chronicle the subjects' help-seeking efforts. Interviews with the youth and their families revealed that recognition is a complicated process involving various players in a dynamic social process (Boydell et al., 2013). Additionally, Wilson, Bushnell, and Caputi (2011) conducted a review of relevant help-seeking literature, and determined that one of the most prominent barriers to treatment seeking for young people was a lack of recognition—both individually and within the social network—due to "incomplete mental health and emotional literacy" (p. 34).

Sometimes referred to as *perception of need* (Horwitz, Gary, Briggs-Gowan, & Carter, 2003), *problem definition* (Cornally & McCarthy, 2011), *problem interpretation* (Cauce et al., 2002), *lay diagnosis* (Biddle et al., 2007), or encompassed within constructs such as *explanatory models* (Johnson, Sathyaseelan, Charles, Jeyaseelan, & Jacob, 2012; Kiropoulos & Bauer, 2011) or *making* or *attaching meaning* (Mackenzie, Erickson, Deane, & Wright, 2014; Thomson et al., 2012), the ultimate conclusion is that if a parent does not understand, interpret, define, perceive, or recognize that their child's behaviors stem from mental illness, they will be unlikely to seek help from mental health professionals (Coles & Coleman, 2010). Thus established as a specific area or process warranting study, it is important to consider those factors that seem to have the most impact on parental help-seeking, and specifically their recognition of their child's mental illness.

Factors Affecting Parental Recognition and Help-seeking

How does a parent learn to recognize mental illness? For that matter, what exactly is recognition? The etymology reveals the Latin root of *cognosce* (2014), meaning *knowing or being thoroughly acquainted with*, coupled with the prefix *re-*, which means *again*. Thus the word recognition literally means *to know again*. From a psychological perspective, recognition occurs when an individual identifies previous experience with a stimuli (Gerrig & Zimbardo, 2002)—therefore, a person cannot recognize something if they do not have a prior connection with it. Contrast recognition with the act of being *aware* (2014), meaning *to know or be sensible of*. Awareness does not require prior knowledge or experience. Thus, a parent can be aware of their child's problem behaviors, yet not recognize those behaviors as being related to mental illness. This is where an understanding of recognition—as a process—becomes important.

Recognizing a child's mental illness is far from automatic, and is typically a complicated and protracted process that occurs as a result of discounting all other possible explanations (Saunders & Bowersox, 2007). In the PMP model, the first step depicted is when parents initially become aware of the child's distress (Logan & King, 2001) or their problem behaviors. Then a variety of environmental inputs augment the parent's awareness, potentially enabling progress to the second stage of recognizing the problem as both psychological in nature and significant enough to warrant care (Logan & King, 2001). Unfortunately, the PMP model is not sufficiently detailed to include the plethora of potential inputs that can enhance or impede recognition of childhood mental illness, so this section will present eight dominant, recurring themes from the scholarly literature on variables influencing parental recognition and help-seeking.

Distress and Crisis

A topic that permeated the literature on recognition of mental illness for adults, adolescents, and children was the prominence of distress. Typically the distress progressed until a breaking point was reached, and this crisis typically served as a trigger or predictor for service use (Horwitz et al., 2003). While parents were typically worried that their child was experiencing distress, it was not so much the child's distress that prompted recognition or action (Zwaanswijk et al., 2003), but rather an accumulation of a seemingly insurmountable level of burden to the parents or the family (Oldershaw, Richards, Simic, & Schmidt, 2008). The distressful events most commonly cited as reasons for consulting a professional included disruptions to family social life or leisure time (Duchovic, Gerkensmeyer, & Wu, 2009; Simpson, Cohen, Bloom, & Blumberg, 2009; Tahhan, Pierre, Stewart, Leschied, & Cook, 2010), conflicts with parental employment or financial difficulties related to the child's distress (Duchovic et al., 2009; Sayal, 2006), and threats to feelings of self-esteem or self-efficacy as a parent (Boulter & Rickwood, 2013; Sayal et al., 2010b; Sheppard, 2006).

A parent's level of tolerance for disruptive behavior was related to their perception of distress, and Wright et al. (2013) observed some gender differences in tolerance levels—while mothers seemed to have the same level of tolerance for both their son's and their daughter's oppositional behaviors, fathers were more tolerant of their boy's defiant behaviors (Wright et al., 2013). Cultural differences in tolerance have also been noted, with Latina mothers exhibiting a higher level of tolerance of their child's disruptive behavior (Arcia, & Fernandez, 2003).

There was typically a significant gap—often several years—between initial awareness of a problem and obtainment of care (Bussing, Zima, Gary, & Garvan, 2003; Jenkins, Youngstrom, Washburn, & Youngstrom, 2011; Jorm, 2012; Moses, 2011; Reid et al., 2006). Moses (2011) performed a cross-sectional, mixed-method study of 70 parents of adolescents in a treatment program, and found an average of 2 years from problem awareness to initial treatment. Similarly, in their interview study of 300 parents who had called any of 16 mental health facilities in Ontario, Canada, Reid et al. (2006) learned that parental concerns emerged an average of 3.7 years before treatment was sought.

Recognition was never depicted as a sudden flash of insight; rather, it was consistently described as a protracted and evolving process of parental observation, worry, and assessment against standards, often building to a crisis where parents felt stretched beyond their limits (Singer, 2009; Tahhan et al., 2010; Wilson, Cruickshank, & Lea, 2012). In their phenomenological study of families in rural Australia, Wilson et al. (2012) identified an extraordinary level of prolonged parental emotional burden, involving helplessness, powerlessness, and hopelessness as their child's behaviors escalated. This period of delay and the accompanying normalization featured prominently in the literature.

Delays, Avoidance, and Normalization

Normalization occurs when an individual redefines abnormal or dysfunctional symptoms as within the range of typical, everyday distress (Biddle et al., 2007), or minimizes the negative effects of the problems (Saunders & Bowersox, 2007). While this phenomenon is observed in relation to many medical conditions (Moffat, 2010), normalization is particularly prevalent in mental illness cases because of the gradual onset of symptoms, coupled with the imprecision and subjective interpretation of terms such as *depression* and *stress* (Biddle et al., 2007; Mechanic, 1995).

Delays, avoidance, and normalization can result when parents underestimate the significance of the behaviors (Thomson et al., 2012), assume the behaviors are part of a normal developmental phase (Oldershaw et al., 2008), or overemphasize aspects of the child's environment in addition to their behaviors (Schnitzer, Loots, Escudero, & Schechter, 2009). Even if parents are aware that their child's behaviors are extreme, the "wait and see approach" (Oldershaw et al., 2008, p. 141) or excessive attempts to cope with the behaviors (Singer, 2009) can extend into years, and the younger the child, the longer the period of delay (Christiana et al., 2000; Reid et al., 2006). If there is no input from the social network to indicate that behaviors are outside of the normal range (Arcia, & Fernandez, 2003; Brown, 2012), the period of delay and normalization will typically be extended until a crisis occurs (Biddle et al., 2007; Epstein et al., 2010).

Social Network

A parent's social network plays a pivotal role in both recognition and help-seeking. The majority of the time, the parent was the first person to become aware of the child’s distress or inappropriate behaviors (Boulter & Rickwood, 2013), and most typically this parent was the mother (Reid et al., 2006). However, parents rarely relied on their own perceptions, and usually required confirmation or legitimization from their social networks (Arcia & Fernandez, 2003; Singer, 2009; Thomson et al., 2012). These social networks could be comprised of family members, friends (Lindsey, Chambers, Pohle, Beall, & Lucksted, 2012), school or religious personnel (Murry et al, 2011), or general practice physicians (Sayal et al., 2010b), but often also included other societal elements such as the internet, media (Epstein et al., 2010), and the justice system (Watson et al., 2009). Arcia and Fernandez (2003) interviewed 63 Latina mothers of children with symptoms of disruptive disorders, and found that reports of problems from school personnel were most likely to prompt parental concern, although inputs from other family members also enhanced recognition. In their phenomenological study of eight parents of pre-teen and teens with anorexia nervosa, Thomson et al. (2012) learned that primary care physicians were typically the first resource contacted within the parent’s network.

While most frequently a social network was cited as an asset in recognizing mental illness or suggesting treatment, several studies identified a parent’s social network as a detriment or barrier to either recognition or help-seeking. When spouses, family members, or prestigious others disagreed with the parent’s observations, or had contrary opinions about use of mental health services, this could become a powerful influence (Lindsey et al., 2012). Only when the parent was driven to the breaking point did they typically distance themselves from or override opposition from their social network (Watson et al., 2009) in order to obtain treatment for their child.

Culture provides an overarching framework for an individual’s social network, forming and contributing to attitudes, beliefs, education, and norms. Thus a parent’s communities contribute to several of the variables influencing parental recognition and help-seeking, specifically stigma, stoicism, understanding of mental illness, and explanatory models.

Stigma. Stigma is a negative reaction or response from a social network, which stems from assumptions about differences or inferiority (Gerrig & Zimbardo, 2002). Prior, Wood, Lewis, and Pill (2003) used qualitative focus groups from a cross-section of primary care attendees in Wales to demonstrate that often these assumptions are of a moral nature, while the literature review conducted by Saunders and Bowersox (2007) highlighted that these moral assumptions are often related to a supposed “weakness [or] badness” (p. 104) of character. In the literature, stigma was often conflated with its consequences, which include prejudice and discrimination, labelling, disruption of social interactions (Prior et al., 2003), and blame for their illness (Saunders & Bowersox, 2007). Thus, stigma presented frequently as a barrier to both recognition and treatment seeking. Stigma can be real or perceived, and can stem from outside the individual or may manifest as self-stigma. Worry about stigma and its consequences elicited a variety of responses from parents.

Some parents responded to stigma by detaching themselves from their social networks in order to preempt rejection or disapproval for themselves of their child (Watson et al., 2009), while others hid their distress and denied connection with mental illness, which negated the possibility of obtaining support from their network (Watson et al., 2009). The fear of being blamed for their child's behaviors or illness was frequently cited (Mukolo & Heflinger, 2011; Sayal et al., 2010b), as well as fear of marginalization for themselves or their child (Murry et al., 2011; Wilson et al., 2012). In some cases, these fears of stigma were compounded by perceived expectations of stoicism and self-reliance.

Stoicism. As a philosophy, Stoicism focused on alleviating suffering though logic, understanding, and correct judgment (Eells, 2012). The Stoic philosophers of ancient Greece were known for their austerity, control of emotion, and patient endurance, while more modern images of stoicism conjure self-reliant and independent pioneers. To some degree, stoicism is the antithesis of help-seeking, and attitudes that convey self-management and the ability to solve one's own problems are frequently offered as justification for not obtaining treatment for mental illness (Christiana et al., 2000; Thompson, Hunt, & Issakidis, 2004; Wilson et al., 2011). For many parents, although more often for fathers, admitting the need for help can result in shame or stigma (Saunders & Bowersox, 2007). Wanting to manage the problem themselves not only typically resulted in the longest delays (Christiana et al., 2000), but could also lead to more severe, punitive discipline due to the parent's perceived inability to manage their child's behaviors (Morrissey-Kane & Prinz, 1999).

Previous understanding of mental illness. Since the meaning of the word *recognition* encompasses knowing again, it follows that a prior experience or previous understanding of mental illness would facilitate parental recognition of their child's disorder. The literature supports this, emphasizing that mental health problems in the parent not only increased problem recognition in their child (Zwaanswijk et al., 2003), but also served as a predictor of recognition (Sayal, 2006). The converse was also supported—that lack of experience with or no previous knowledge about mental illness typically produced barriers or delays to recognition (Boydell et al., 2013; Henderson et al., 2013; Thompson et al., 2004).

However, although prior experience improved or predicted recognition of childhood mental illness, it did not necessarily enhance treatment seeking. General knowledge about mental health or psychology could predict intentions to seek help (Henderson et al., 2013), but did not always correlate with actual treatment seeking (Zwaanswijk et al., 2003). Parents who were currently receiving treatment for their own mental illness (Zwaanswijk et al., 2003; Murray et al, 2011) or who were aware of mental disorders in other family members (Boulter & Rickwood, 2013) were more likely to obtain treatment for their child. Thus the quality of their own previous experience may affect the likelihood of their seeking treatment for their child (Murray et al, 2011).

Explanatory models and attribution. How a parent contextualizes or frames their child's behaviors will depend on how they explain the origins of those behaviors. Explanatory models of illness are culturally bound (Kiropoulos & Bauer, 2011), and include an individual's beliefs about the etiology or causes of the illness, the meaning of symptoms, the course of treatment, and the expectations of affected individuals (Jacob, 2010). Thus, understanding how parents, families, and communities define problem behaviors and attribute reasons for the behaviors is vital to a study of recognition and subsequent help-seeking.

The process of defining and conceptualizing mental illness is an ongoing and dynamic activity, influenced by numerous environmental factors and experiences (Kiropoulos & Bauer, 2011). Parents may attribute the problems to a medical condition, or they acquire an alternative explanation (Bussing et al., 2003) such as disposition, luck, or peer influence (Morrissey-Kane & Prinz, 1999). Additionally, it is possible—and even common—for an individual to simultaneously hold multiple, seemingly contradictory explanatory models for mental illness and a child's behaviors (Jacob, 2010; Johnson et al., 2012). Parents reconciled religious beliefs with western medicine by simultaneously embracing both natural and supernatural explanations for their child's behaviors—for example, an illness that was brought on by the will of god, black magic, or bad luck (Jacob, 2010; Johnson et al., 2012; Schnitzer et al., 2009). Often attributions of genetic or biological causes are concurrently maintained with beliefs in social, environmental, or situational causes. Examples of this occur when parents acknowledged an illness but also credited a developmental phase or behavioral attribute (Watson et al., 2009) as causal, or when parents simultaneously accepted psychological factors or inborn personality characteristics (Schnitzer et al., 2009) along with childhood adversity or parental blame (Crowe et al., 2011).

Making meaning. Attribution and explanatory models underpin a parent's ability to make meaning of and understand their child's illness, and thus recognition becomes, in part, a narrative process (Johnson et al., 2012) that is tied to a parent's self-concept (Tekin, 2011) and identity as a parent (Thomson et al., 2012). As they begin to consider the possibility of mental illness, a parent must reconcile their previously held beliefs, not only about mental illness *per se*, but also about the types of parents who have mentally ill children (Thomson et al., 2012) and what this may mean to their family identity. Often parents are afraid of blame (Watson et al., 2009) or engage in self-blame (Crowe et al., 2011; Sayal et al., 2010b), and the resulting identity conflict typically leads to denial, avoidance, or delay in both recognition and treatment (Farmer, Farrand, & O'Mahen, 2012). Moses (2011) reports that it is still unclear whether conceptualizing problems as psychiatric conditions is beneficial for parents, due to the high levels of distress involved, while other authors describe a sense of relief when parents are able to process and make sense of their child’s behavior as an illness (Kokanovic et al., 2013; Richardson, Cobham, McDermott, & Murray, 2013; Tahhan et al., 2010). Kokanovic et al. (2013) accomplished a secondary data analysis of interviews conducted for an Australian study on the management of depression. The authors discovered that participants sought meaning through creating personal illness narratives, and often found relief in identifying a cause for their feelings (Kokanovic et al., 2013). Conversely, Richardson et al. (2013) learned that while relief was experienced by some parents, the overriding emotions characteristic of most parents’ experience were loss and grief. Although the focus of their study was post-diagnosis, their inductive thematic analysis of 15 caregivers revealed that feelings of grief and loss were persistent throughout the recognition phase (Richardson et al., 2013).

Community Systems and Policies

Since both recognition and help seeking are social processes, the systems and policies that surround families in their communities play a significant role in a parent’s ability to recognize their child’s disorders and obtain treatment (Boulter & Rickwood, 2013). Systems, and the people within those organizations, can help parents understand the differences between normal, typical, adaptive behaviors and those stemming from a disorder (Thomson et al., 2012), enhancing the likelihood that recognition can be achieved and help seeking can be advanced. Four systems and public policy arenas emerged in the literature as most likely to impact both parental recognition and subsequent care: the education system, the health care system, the public health system, and the criminal justice system. This does not downplay the importance of other systems such as child welfare, but instead focuses on those areas most germane to the early stages of recognition and help-seeking.

Education system. School environments hold the greatest potential for assisting parents in the processes of both recognition and help-seeking. Children spend a large percentage of their waking hours in the school environment, and some researchers indicate that teachers and education staff are typically the first, and sometimes the only professionals that parents or adolescents consult about their concerns (Boydell et al., 2013; Koppelman, 2004; Sayal et al., 2006). Additionally, while parents are usually the first to become aware that some sort of problem exists, teachers are typically the first to recognize that the problem may be related to a disorder (Bevaart et al., 2012; Loades & Mastroyannopoulou, 2010), and the first element of the social network to suggest this possibility to parents (Arcia & Fernandez, 2003; Lindsey et al., 2012; Murry et al., 2011) and encourage further help-seeking (Zwaanswijk et al., 2003). Using focus groups to explore the help-seeking behaviors of 16 urban African American adolescents and 11 of their caregivers, Lindsey et al. (2012) found that an important construct emerged outside of their theoretical framework: “Reliance on School Staff in the Context of Providing Help” (p. 116). Murry et al. (2011) also found that school counselors and teachers were highly endorsed in their mixed methods study of rural African American mothers, with teachers typically among the first to identify and refer children for mental health services. At times, schools also served as a community nexus for resources such as counseling, parenting classes, and other referral and support services (Murry et al., 2011). Reports from school personnel also served as a bridge to subsequent recognition by the family’s physician (Zwaanswijk et al., 2003).

Health care system. Although general practitioners (GPs) and pediatricians are the members of the social network that usually possess the most training in mental disorders, their rates of recognition are low, often because parents do not bring their concerns forward (Sayal et al., 2010b). Parents are often confused about the distinction between normative and atypical childhood behaviors, and frequently do not articulate concerns to the doctor (Ellingson, Briggs-Gowan, Carter, & Horwitz, 2004). Thus an interesting cycle develops—if parents do not recognize mental illness, GPs will not receive the inputs they need to recognize the problem, and cannot facilitate the parent’s recognition. Horwitz et al. (2003) suggested that the current structure of the pediatric health system unwittingly facilitates this cycle, since there is limited access to and lack of availability of professional mental health services, especially when contrasted with available services for developmental problems. In other words, physicians are better trained to identify and respond to developmental delays, and the system is geared to provide these services, but a parallel level of doctor preparation and service availability for mental and behavioral problems is lacking, which perpetuates the self-fulfilling prophecy of lack of recognition by both parents and physicians (Horwitz et al., 2003).

Another element that appears to compound this cycle of mutual non-recognition is the indication that GPs must go through the same process of recognition that parents do, involving applying their own explanatory models and tendency to normalize behaviors (Thomson et al., 2012). This can result in extended delays for specialty treatment, especially since parents often require a crisis to generate their own recognition and help-seeking.

Public health system. Problems often escalate to the point of a crisis because little guidance is available to help adults discern early warning signs of mental illness or distress (Erritty & Wydell, 2013; Logan & King, 2001). Research is accruing that demonstrates the need for and importance of effective public health campaigns promoting recognition and understanding of mental illness (Henderson et al., 2013), and improving mental health literacy (Thompson et al., 2004; Wilson et al., 2011). Additionally, there is an upward trend in the effectiveness of these types of public health initiatives in generating support for recognition and treatment seeking for mental illness (Pescosolido, Martin, Long, Medina, Phelan, & Link, 2010; Saunders & Bowersox, 2007).

Criminal justice system. Unfortunately for many families and communities, the crisis that precipitates recognition of childhood mental illness frequently involves an interaction with the legal system. In some communities the juvenile justice system is the primary means of referral for mental health issues, particularly for adolescents (Murry et al, 2011; Watson, et al., 2009). This has resulted in a disproportionately higher proportion of children and adolescents in the juvenile justice system with a diagnosable mental illness than is typical in the general population—while an estimated 20% of children suffer from a mental disorder, 67-70% of children in the justice system are afflicted (Stagman & Cooper, 2010). These types of statistics warrant an examination of the current policies and practices in communities that are related to the recognition and treatment of childhood mental illness.

Public Policy and Parental Help-Seeking

From a public policy perspective, the document that has had far-reaching impact on children's mental health in the United States was the seminal report by the Surgeon General on mental health (HHS, 1999). The first report to examine our country's attitudes about and efforts surrounding mental illness and mental health, the report highlighted disturbing facts, including the pervasiveness of mental illness at approximately 20% of the population, the high level of burden of disease with mental illness ranked as the leading cause of disability, and the affirmation that "children and adolescents can and do develop mental disorders" (HHS, 1999, p. 17) at the same rate as adults. The information in this report prompted the formation of the President's New Freedom Commission on Mental Health (PNFCMH, 2003), which placed emphasis on promotion of childhood mental health, and established action goals for expansion of school mental health programs and for screening across the lifespan. These calls to action have resulted in subsequent policy guidance from the Substance Abuse and Mental Health Services Administration (SAMHSA), which has sought to improve collaborative efforts between child-serving organizations such as primary care health providers, schools, and child welfare settings (SAMHSA, 2011). The initiatives that impacted this study include goals for whole-community, systems of care approaches, specifically the use of school-based health centers.

Systems of Care

In response to the second goal articulated by the PNFCMH, mental health care will ideally be “consumer and family driven” (PNFCMH, 2003, p. 8). In the past decade progress towards this goal has resulted in many states and communities developing a *systems of care* (SOC) approach to ensure coordination between a variety of service organizations (SAMHSA, 2011). The SOC approach strives for individualized care in which wraparound services ensure the child’s ability to both remain at home and function in their community (SAMHSA, 2011). To this end, the agencies and systems will jointly consider the physical, emotional, cultural, educational, and social needs of the child and their family (Jensen et al., 2011). An example of a wraparound SOC is the school-based health center concept, where community providers gather in a central, family-friendly location to serve the child’s multi-faceted physical and mental health needs (Koppelman, 2004). Studies are accruing that indicate the effectiveness of school-based health programs as both a comprehensive SOC approach (Griffiths & Christensen, 2007; Walter et al., 2011), and a means to enhance understanding about mental illness in the community (Mendenhall & Frauenholtz, 2013).

School Based Health Centers

Locating health facilities on school campuses began over 40 years ago, growing out of concern for various public health needs (Keeton et al., 2012). The connection seems reasonable, since children spend the majority of their waking hours in the school setting, and since physical and mental health are foundational to learning (PNFCMH, 2003). Over the decades favorable evidence accrued, and the list of services provided by school based health centers (SBHCs) continued to grow (Keeton et al., 2012). Today, there are more than 1,900 SBHCs nationwide (Keeton et al., 2012; National Assembly on School-Based Health Care [NASBHC], 2012) in 45 states (Amaral, Geierstanger, Soleimanpour, & Brindis, 2011), with 18 states specifically investing funds in SBHCs (School-Based Health Alliance [SBHA], 2014). Recent federal legislation such as the Healthy Schools Act, the Children’s Health Insurance Program (CHIP), and the ACA have supported this expansion; however, the growth is driven predominantly by policies and funding at the state and community levels (SBHA, n.d.), in order to improve access to care for high-risk and underserved children (Keeton et al., 2012; School-Based Health Center Grant Program Bill, 2006).

School based health centers have evolved into collaborative partnerships between schools, medical providers, and communities (Colorado Health Institute, n.d.; Gampetro, Wojciechowski, & Amer, 2012). Their goals include improving primary and preventive care to ensure children are healthy and able to learn (Keeton et al., 2012), and most frequently they are located in areas where youth and families have limited access to care (Sharff, Sebastian, Ramos, Adams, & Fairbrother, 2014). Nationwide there is a wide variety in programs, management, and funding sources, yet generally SBHCs can be grouped into five main delivery models: (a) school-financed services, (b) formal partnerships with mental health agencies, (c) school district-sponsored facilities, (d) curricular-based classroom instruction, and (e) integrated practices (Perreault, 2013). The majority of SBHCs in the country (68%) are operated or sponsored by a local health care organization, 12% are sponsored by a school or school district, and the remaining 20% are sponsored by other community organizations such as universities and nonprofit agencies (Keeton et al., 2012). The delivery of services can differ markedly depending on which agency bears the primary responsibility for the administration of the SBHC, particularly in the area of mental health. For example, SBHCs governed by school personnel are more likely to focus on academic outcomes, whereas mental health professionals may place more of an emphasis on a holistic approach to wellness (Perreault, 2013).

Despite these variances, there is strong evidence that SBHCs increase access to care (Sharff et al., 2014) for both physical and mental health needs. Since this study examined the effects of SBHC policies and programs on parental perception of their child’s mental health, two types of services will be considered more fully in this section—research on curricular mental health programs, and clinical mental health initiatives in SBHCs.

Curricular and education-based mental health services. Given the theoretical foundations in education, much of the literature on curricular-based services focused on academic performance outcomes, although some evidence was emerging about the impact on school and community cultures. Generally, the outcomes of educationally based interventions were positive, citing significant improvement on school performance, achievement tests, and social and emotional skills (Knapp, McDaid, & Parsonage, 2011; Weare & Nind, 2011), as well as reductions in bullying, violence (Weare & Nind, 2011), and out-of-school suspensions (Kang-Yi, Mandell, & Hadley, 2013). These types of programs were typically cost-effective, both directly and indirectly in the form of savings on crime-related incidents in the community (Knapp et al., 2011). However, the positive effects of curricular-based programs were heightened when combined with comprehensive, in-school mental health services (Kang-Yi et al., 2013; Knapp et al., 2011; Weare & Nind, 2011). A whole-school approach impacted the values, attitudes, and culture of the school regarding mental health, specifically the interactions staff and students (Weare & Nind, 2011).

Clinical mental health services. Evidence is growing that SBHCs can be an effective component of a community's mental health service delivery strategy (Amaral et al., 2011) for several reasons. First, students with the greatest levels of mental health needs preferred SBHCs over other healthcare options (Amaral et al., 2011, p. 142). Children at schools with SBHCs were five times more likely to have their mental health needs identified and receive services (Gall et al., 2000), while adolescents were 10 to 21 times more likely to receive mental health treatment at a SBHC than at a non-co-located health facility (Gampetro et al., 2012; Keeton et al., 2012). Rates of stigmatization were lower, and the convenient location facilitated the frequent follow-up visits that are typically a component of successful treatment (Keeton et al., 2012). Further, SBHCs offer opportunities for preventive care and early identification (Keeton et al., 2012), which is important since outcomes improve with early diagnosis and treatment of emotional and behavioral health problems (Koppelman, 2004).

Despite the potential for SBHCs to benefit students, policies and funding still fall short of the promise. Since public schools have become the *de facto* system of mental health care for children (Gall et al., 2000) due in large part to the predominance of special education laws (Jensen, 2013), policies that call for better integration of SBHCs into the mental health care system are necessary (Rickwood, 2011). Much of the funding for educationally based services focus on providing special education accommodations after a diagnosis, rather than on early intervention and treatment (Heller, 2014), and the outlook for funding from school budgets is poor (Kaplan, Calonge, Guernsey, & Hanrahan, 1998). Further, although more than 75% of SBHCs offer on-site mental health services (Keeton et al., 2012), staffing shortfalls are common, especially for school psychologists (Heller, 2014).

Since federal funding for SBHCs is scarce, states and communities typically generate the majority of funds and policies for their local SBHCs (SBHA, n.d.). Colorado was one of the first states to provide school-based health care, opening its first SBHC in 1978. Examples of their policies, funding priorities, and integrated programs will be presented in the next section.

Colorado Policies and Programs for School Based Health Centers

Established over 30 years ago as a health financing safety net (Colorado Association for School-Based Health Care [CASBHC], 2011b), the purpose of SBHCs in

Colorado is to ensure that children and adolescents have access to both primary medical and behavioral health care (Colorado Department of Public Health & Environment [CDPHE], 2013). By statute, a SBHC is operated on public school property as a cooperative venture between community agencies (School-Based Health Center Grant Program Bill, 2006). In 2014, Colorado maintained 54 SBHCs, hosted by 21 of the state's 178 school districts (CASBHC, 2014).

Colorado is one of only 18 states that provides state-directed funds for their SBHCs (NASBHC, 2012). In 2011, Colorado allocated over $1.2 million for SBHCs (School-Based Health Alliance, 2014), of which 78.5% came from the state general fund with the remainder from grants and other sources (NASBHC, 2012). As a result of recent legislation at both the federal and state levels, Colorado will receive over $2.5 million in grant aid from a provision in the ACA (Colorado Health Institute, n.d.), and school districts will benefit from nearly $2.5 million in tax money from revenues on sales of marijuana (Robles, 2014). The state's investment appears to be paying off, with two dollars in savings accrued for every dollar spent, and research demonstrating that children with access to a SBHC are both healthier and academically fit than their peers without SBHC services (CASBHC, 2011a).

Colorado is also one of the few states that has established standards and benchmarks for quality in SBHCs throughout the state. Some of the state's guiding principles that are most appropriate to highlight for this study include collaborative relationships between school and community stakeholders, service provision using a youth- and family-centered approach, and an emphasis on preventive services (CDPHE, 2009). Staffing standards stipulate that each SBHC will have a minimum of one on-site behavioral health provider (CDPHE, 2009), and many centers are staffed to assess and treat mental health issues (CASBHC, 2011b); however, diagnosis of psychological disorders within a SBHC is not provided.

Although the outlook for Colorado SBHCs in general is optimistic, several challenges have been identified in providing integrated behavioral and mental health services, including insufficient funding, administrative complexities, and accounting considerations (CASBHC, 2011b). Additionally, current policies on provision of mental health services constrain the availability of funding for prevention and early intervention for mental health needs, since much of the funding for mental health needs is contingent upon a prior diagnosis of a *serious emotional disturbance*, or SED (CASBHC, 2011b).

Parents and SBHCs

When parents, families, and communities are involved together, interventions and treatments are more effective and sustainable (Alegría et al., 2012; Weare & Nind, 2011). However, while there is a growing body of literature on the effectiveness of SBHCs from the perspective of policy makers, and also from the standpoint of adolescents, school personnel, and health providers, little research has been conducted on parental satisfaction with SBHCs (O'Leary et al., 2013). In Colorado, parents must sign a consent form in order for their children under the age of 15 to receive certain services at a SBHC (Colorado Department of Education [CDE], 2007), so it is not unreasonable to conclude that parents’ support of SBHCs might be inferred from the statistics gathered about their use of the facility. There is also anecdotal evidence based on parent and youth advocacy for SBHCs in their community (Keeton et al., 2012). Yet despite the importance of parental involvement, few studies have examined the use or effectiveness of SBHCs from the understanding of the parent. By inquiring into the role that SBHCs play in a parent's perception of their child's mental illness, this study may provide further insights into the effectiveness of SBHCs for the community.

Research Design and Approach

In this concurrent mixed methods study I sought to explore the process of how parents and caregivers in the Pikes Peak Region of Colorado learned to recognize their child's behaviors as resulting from mental illness, and how the presence or absence of a school-based health center affected their recognition process and initial decision to seek treatment.

Rationale for a Mixed Methods Methodology

My decision to select a mixed methods approach emerged from my constructivist worldview, was enhanced by a penchant for pragmatism, and was aided by my understanding that triangulation of methods permits the exploration of the multiple perspectives and realities inherent in any study (Hastings, 2010). Mixed methods research (MMR) synergistically blends elements of both qualitative and quantitative methodologies so that the effectiveness of a study is enhanced, and the understanding is more comprehensive than if only one paradigm had been used (Creswell, 2009). In MMR, not only can the limitations of one approach be offset by the advantages of the other, but the results can be strengthened as the use of one research paradigm can be used to verify findings or elicit meanings from the alternate research tradition (Onwuegbuzie & Leech, 2005).

In order to obtain a broader and deeper understanding of the phenomenon, I drew upon the typology of reasons for mixing methods developed by Greene, Caracelli, and Graham (1989), which include triangulation, complementarity, development, initiation, and expansion (Creswell & Plano Clark, 2011; Greene, Caracelli, & Graham, 1989). My two predominant reasons for combining multiple qualitative techniques with quantitative methodologies in this study were *triangulation* and *complementarity* (Greene et al., 1989). Triangulation results in an in-depth understanding of the research question (Denzin, 2012) through convergence and corroboration of the results from the various methods (Greene et al., 1989). Complementarity enhances breadth of knowledge by using the results from the different methods to elaborate, enhance, and clarify different aspects of the research phenomenon (Greene et al., 1989).

Justification for the Methodological Paradigms

For this study I utilized a convergent parallel design, with a predominant qualitative strand that was enriched by a quantitative strand during the data collection, analysis, and reporting phases. This balance was appropriate since the overarching purpose of the study was to investigate and understand the common experiences of parents in their perceptual processes, with measurement and correlation serving to enhance this understanding. To support this purpose, I rooted the qualitative strand in the phenomenological tradition, augmented by elements of poetic inquiry, while the quantitative strand rested on a cross-sectional design. I present a detailed justification for the use of each strand below.

The qualitative strand. During the selection of the qualitative methodology, I found it useful to determine which approaches were not suitable. A case study approach would have been too broad, not only because of its emphasis on obtaining data from a variety of external sources, but also because it would have been problematic to bind this issue to a single case with a common context (Creswell, 2013). Conversely, a narrative paradigm would have provided too narrow of a focus, precluding the shared experience of multiple participants (Creswell, 2013). Since the population for this study was comprised of a variety of school districts within the state of Colorado, this precluded use of the ethnographic tradition, with its concentration on the shared culture of the participants (Creswell, 2013). Finally, the purpose of this research was not to build a theory or an explanation, so grounded theory techniques (Creswell, 2013) would not have been appropriate. Thus, given the importance of understanding the shared, lived experiences of a variety of participants (Creswell, 2013), the best fit for this research study proved to be a phenomenology.

Phenomenology. A phenomenological study can facilitate a deeper understanding about a central phenomenon, and results can be used to develop policies or implement practices (Creswell, 2013). It explores a single concept with a group of individuals, all of whom have experienced the central phenomenon (Creswell, 2013; Patton, 2002), specifically focusing on how they consciously process their past experiences (Patton, 2002). The primary purpose of a phenomenological study is to distill numerous individual perceptions into a common, universal experience, known as the "essence" (Creswell, 2013; Patton, 2002). Another characteristic feature of a phenomenological approach involves the need for the researcher to recognize, identify, and then set aside their own experiences with the phenomenon, a concept known as "*epoche* (or bracketing)" (Creswell, 2013, p. 80).

I constructed the protocol for the qualitative strand around the four steps in Moustakas' (1994) transcendental phenomenology model, specifically (a) *epoche*, (b) phenomenological reduction, (c) imaginative variation, and (d) synthesis. The first step of epoche involved identifying and then setting aside the researcher's preconceived ideas, judgments, experiences, and biases (Moustakas, 1994). This pre-reflective step was particularly important due to the researcher's personal experiences with the phenomenon of recognizing their own child's mental illness. In the second step of phenomenological reduction, I incorporated a cycle of observation and description of the data as it appeared, followed by reduction of the data to that which was most germane to the research question, and finally *horizonalizing* the data so that each statement was perceived with equal value (Moustakas, 1994). During the phase of imaginative variation, I sought multiple possible meanings in order to illuminate the emerging themes inherent in the phenomenon, with specific focus on descriptions of *what* the participants experienced, and *how* they experienced the phenomenon (Moustakas, 1994; Patton, 2002). In the final stage of synthesis, I melded and synthesized the themes and meanings obtained in the previous steps into the *essence* of the experience (Moustakas, 1994).

To augment the transcendental phenomenological approach, I incorporated elements of poetic inquiry (Prendergast, Leggo, & Sameshima, 2009). Poetry offered natural links with a qualitative phenomenology, and enhanced each stage of the transcendental model, especially as a way to achieve new insights and perspectives (McCullis, 2013).

Poetic inquiry. A fusing of art and science, poetic inquiry is a form of qualitative research that includes poetry as a component of research (Prendergast, 2009). Like narrative inquiry, poetic inquiry uses the literary arts and poetic devices to more fully and authentically convey the meaning of human experiences (Prendergast, 2009). First emerging as a discipline in the 1980's, poetic inquiry has been growing among qualitative researchers in the past decade (Dobson, 2012), although it is still perceived as being on the "margins of the world of scholarship" (MacKenzie, 2008, p. 5). Some authors view poetic inquiry as an epistemology, or a way of knowing (MacKenzie, 2008; Prendergast, 2009), while some view it as a reaction to postpositivism (MacKenzie, 2008). There seems to be general consensus that use of poetry can help qualitative researchers recognize, reimagine, and reorganize relationships and thus enhance the understanding and presentation of ideas and meanings (Janesick, 2011; McCulliss, 2013; Prendergast, Leggo, & Sameshima, 2009; Swanson, 2009).

A strength of using poetic inquiry as a component of this qualitative strand emerged from the natural relationships that existed between the two methods. Both phenomenology and poetry seek to explore and describe the essence of the human experience, and both rely on language to express this meaning (Laureate Education, 2010). Since a specific goal of this phenomenological strand was to distill the essence of meaning and to evoke and understand emotions—and since poetry often has similar goals—the melding of methodologies served to enhance the research.

The quantitative strand. I used a cross sectional survey to explore the relationship between various individual factors and parental perception of their child's mental illness, in order to discover which factors had the greatest effect on both inhibiting and enhancing the parental recognition process. My use of this strand enhanced the study by seeking patterns and relations between variables and also by facilitating data collection in a real-life setting (Frankfort-Nachmias & Nachmias, 2008). Although its purpose was not to determine causation, another benefit of the cross sectional design was that this design might permit inferences to be drawn from the study sample to a larger population (Creswell, 2009).

I drew the independent variables from the literature, and included a variety of factors believed to affect recognition and perception such as (a) distress to the family, (b) a perceived crisis event, (c) prior experience with mental illness, and (d) input from members of a parent's social network, especially from school staff and health professionals. Several of these factors were directly related to the presence of a SBHC, and the impact that this public policy decision had on the parental recognition process and initial decision to seek treatment. I defined the dependent variable of perception as a parent's recognition, understanding, and awareness of the concept of mental illness, resulting in defining some of their child's behaviors as having their root in a mental illness that requires care. To assess the relationship between variables, I used a multivariate analysis method.

Summary and Conclusion

In order to diminish the public health crisis inherent in childhood mental illness, which affects nearly 15 million children in the United States alone (American Psychological Association, 2014), communities will benefit from an understanding of the nuances of the help-seeking process. The current understanding of treatment seeking indicates that the act of asking for help is predominantly a social endeavor, influenced by a variety of factors involving social networks, emotions, information and education, policies, and systems. Parental help-seeking for mental illness is also compounded by the effects of stigma, which can impede both treatment and the initial stage of recognition.

Within help-seeking models for mental illness, recognition is considered a universally important precursor to seeking treatment, and the process of recognition is most often characterized by delays and periods of normalization, culminating in significant distress or a crisis. Thus, scholars are beginning to disaggregate the step of recognition into a distinct process, worthy of exploration. This is where this study has the potential to yield benefit, by enhancing the understanding of the process of parental recognition of their child’s mental illness, especially as it contributes to subsequent help-seeking.

A variety of factors have been found to influence the recognition process, including distress, crisis, and social networks. Social networks exert significant influence on parental expectations, attitudes, and explanatory models about their child’s behaviors.

Therefore, as a component of the social network, school-based health centers show great potential for influencing parental recognition and subsequent treatment seeking. Exploring the impact of Colorado's school-based health centers upon the process of recognition will inform and prepare policy makers as they make decisions to assist children with mental health needs.

Chapter 3: Research Method

This chapter specifies my research design and approach for the exploration of Colorado parent's recognition of their child's mental illness, and the impact of school based health centers (SBHCs) on that process. The details are organized into five major content areas: (a) a description of the mixed-methods design and the research questions, (b) the logic behind the selection of the population and the sample, (c) components of the instrumentation, (d) data collection and analysis procedures, and (e) measures taken to ensure the protection of participants' rights.

Research Design

In this study I used a concurrent mixed methods approach to explore the process of how parents in the Pikes Peak Region of Colorado learned to recognize their child's mental illness, and how school-based health centers affected their recognition process and initial decision to seek treatment. The investigation was based on a convergent parallel design with a predominant qualitative strand. Rooted in a phenomenological methodology, the qualitative strand was enhanced by incorporating elements of poetic inquiry. In the quantitative strand I employed a cross-sectional survey technique and a multivariate data analysis to investigate the relationship of various factors to the process of parental recognition.

To facilitate the concurrent gathering of qualitative and quantitative data, I developed an instrument utilizing a standardized open-ended interview format that incorporated both qualitative and quantitative tools. The instrument was comprised of three parts which corresponded to the three phases of the interview: a screening phase, a pre-interview reflection exercise, and a face-to-face interview survey. Each of these phases sought to elicit responses that enabled me to explore the research questions and subquestions.

The two main research questions asked: How do parents describe their experiences of recognizing that their child's behaviors are related to a mental illness that requires treatment? To what extent does the presence of a school-based health center in the community affect parental problem recognition? Other related sub-questions that emerged as a result of delving into the main research questions included:

1. Qualitative research subquestions.
    a) What impedes or enhances parents' perception and initial treatment decisions?
    b) How and why do parents overcome barriers to problem recognition?
2. A quantitative research subquestion.
    a) Which factors will significantly contribute to the percent variance change accounted for in parental problem recognition?

For the quantitative component, I used the following hypotheses to examine the relationship between the independent variables of (a) normalization, (b) explanatory models, (c) stoicism, (d) stigma, (e) previous experience with mental illness, (f) social network, (g) media, (h) distress, (i) crisis, and (j) presence of a SBHC and parental problem recognition:

$H1_O$: The independent variables of (a) normalization, (b) explanatory models, (c) stoicism, (d) stigma, (e) previous experience with mental illness, (f) social network, (g) media, (h) distress, (i) crisis, and (j) presence of a SBHC will not significantly contribute to the percent variance change accounted for in parental problem recognition of their child's mental illness.

$H1_A$: The independent variables of (a) normalization, (b) explanatory models, (c) stoicism, (d) stigma, (e) previous experience with mental illness, (f) social network, (g) media, (h) distress, (i) crisis, and (j) presence of a SBHC will significantly contribute to the percent variance change accounted for in parental problem recognition of their child's mental illness.

Population and Sampling Strategy

Since a phenomenological methodology predominated in this research, a purposeful sampling strategy was most appropriate (Creswell, 2013). Specifically a criterion sampling was called for, wherein all participants must meet the specific criteria of having experienced the topic phenomenon, and being willing to share their lived experiences (Creswell, 2013; Patton, 2002). Additionally, the impact of SBHCs in the community was a key component of the study, so the presence—or absence—of a SBHC was an important consideration when determining the population. To complement the criterion sampling strategy, I also used a snowball or chain sampling approach, wherein well-situated people were asked to approach potential participants through word-of-mouth and networking (Patton, 2002).

Colorado is divided into 178 school districts, with 21 of those districts hosting the state's 54 SBHCs (CASBHC, 2014). In order to obtain a sufficient number of qualified participants, I drew the population for this study from those school districts that had either, (a) multiple SBHCs within the district, (b) a relatively low *per capita* ratio of

SBHCs to district populace, and/or (c) a large number of residents in the surrounding communities. I initially advertised the study in twelve school districts within the Metro, Pikes Peak, and Northwest Regions to maximize the number of participants with access to a SBHC. The advertisements were distributed to a variety of individuals and agencies that provided support to parents of children with psychological disorders including community mental health centers, nonprofit organizations, mental health professionals, and colleges, in addition to the SBHCs.

In order to be eligible for the study, participants needed to have experienced the research phenomenon, and therefore had to be a caregiver responsible for making medical treatment decisions for their child. Additionally, their child must have received an evaluation or diagnosis of a psychological disorder within the past year, as verified by the parent. I established this criterion in order to encompass the initial decision to seek treatment, and also to minimize the effects of recall error which involves the tendency to forget information or purposely misconstrue events for self-serving purposes (Patton, 2002).

While there are no formulas to calculate sample size for a phenomenological study, qualitative scholars suggest a smaller number of participants, typically between three and twenty-five subjects (Creswell, 2013; Patton, 2002). For this study, I set the minimum sample size at five participants, with a target of fifteen. I determined the maximum according to considerations such as saturation or redundancy of information, shortage of time or money, or a paucity of willing, qualified participants (Patton, 2002).

Protocol and Data Collection

Given the concurrent timing of the mixed methods data collection for this research and the variety of approaches to be used, I developed a detailed protocol to unify the components of the study. A protocol functions as a procedural guide for the researcher, and may include elements such as scripts for the introduction and conclusion of the interview, prompts and reminders surrounding the questions, and tools to facilitate note-taking (Jacob & Furgerson, 2012). My use of a protocol also enabled the incorporation of quantitative questions and tools, as well as the blending of poetic inquiry techniques, into the data-gathering instruments.

This protocol reflected my priorities with this mixed methods study in which an inductive, emerging approach dominated, and deductive, quantitative measures were incorporated in order to complement, refine, and confirm the qualitative responses. To facilitate these priorities, I used a combination approach in which the standardized open-ended interview approach served as the trellis for the protocol, and quantitative measures and elements of poetic inquiry were intertwined throughout to supplement the phenomenological methods (Patton, 2002).

The most appropriate data collection methods for this study were the use of interviews and surveys, since it was not possible to observe behaviors that took place in the past (Patton, 2002). I conducted in-depth, face-to-face interviews at a location approved by the participant, which might include an office, a semi-private meeting room, or the interviewee’s home as a last resort. I served as the primary research tool, (Kvale, 2007; Patton, 2002), and developed a three-part protocol comprised of a screening segment, a pre-interview phase, and a semi-structured interview component.

Screening Phase

I developed a script-like guide and questionnaire to be used during the screening phase (see Appendix C). The guide began with an icebreaker, proceeded with questions that determine eligibility, offered a general overview of the subsequent phases of the study, and concluded by requesting contact information and scheduling a date for the interview phase. This progression was designed to accomplish the dual objectives of determining if an inquirer was eligible for and interested in the study, and beginning to establish rapport with those who indicated a desire to participate. My decision to use the guide format based on the presumption that the screening would take place over the telephone, in response to the advertisement (Appendix D) or a referral about the study.

Although the guide was in the form of a questionnaire, it was important for the screener to maintain a conversational tone, since they would also ultimately be serving as the interviewer. The first moments of contact are crucial in a telephone interview in order to prevent a subsequent refusal to participate (Dillman, Gallegos, & Frey, 1976). This initial contact would also form the foundation for future rapport, and would be an investment in conveying empathy and understanding, while withholding judgment (Patton, 2002). Because further social cues in the form of body language and facial expressions would be absent, the interviewer/screener would need to use their acumen and tact to best accomplish both of the screening objectives (Kvale, 2007).

Once it had been determined that the inquirer was eligible for the study and was interested in continuing, the focus of the screening questions shifted to an informational overview. The purpose of this section was to fully inform the prospective participant of the study requirements, specifically the amount of time, the potentially sensitive subject matter, and the request that they compose or find a poem about their experiences. I included this as an element of the screening phase since some people may be dissuaded by these requirements. It also offered an opportunity to address concerns and questions that the individual may have had about their participation. I used the final section of the questionnaire to obtain the participant's contact information so they could receive the materials required for the pre-interview phase.

Pre-Interview Phase

The tool for this phase took the form of a written questionnaire (Appendix E), and was mailed to the participant either in hard copy or via email. Its four major purposes were to: (a) obtain informed consent for this phase of the data collection, (b) gather basic demographic information about the participant and their experience, (c) encourage a period of reflection in advance of the interview phase, and (d) request their selection or composition of a poem relating to their recognition experiences and/or emotions.

Combining these four tasks into a separate phase enabled a more productive use of the face-to-face interview time, for several reasons. First, it offered a more efficient means of gathering routine demographic information, which allowed the participant to use their energies during the interview for detailed recollections and narratives. Second, beginning the reflective process in advance of the interview should have enabled deeper and richer responses during the session (Janesick, 2011). It might also have reminded the participant of other information that they might contribute such as documents or photographs. Finally, they may recall societal and contextual data such as films, television programs, novels, and poetry (Creswell, 2013), which could augment the interview transcripts.

The request for a poem from the participant—either original or found—was the most important reason for this section of the data collection instrument. By using a variety of writing formats to stimulate ideas and shape understanding of concepts, poetry can activate the thought processes of both the participant and researcher (McCulliss, 2013; Prendergast et al., 2009). Both poetry and phenomenological research strive to genuinely represent the essence of human experiences (Prendergast, 2009), and both rely on the practices of observation, listening, and noticing (Swanson, 2009). Poetry is especially effective at accessing, revealing, and representing deep emotions (McCulliss, 2013; Prendergast, 2009). Asking the participant to go through the process of translating or expressing their experiences in a poetic format could have added richness and depth to their reflections and subsequent interview narrative.

Requesting that participants write poetry specifically for a research study as a form of data collection is rare. It is slightly more common to find these types of appeals in educational or language research within classrooms, where students are asked to write poetry as part of an assignment or academic skill assessment (Chrisler, 1992; Christianakis, 2011; Gere, Buehler, Dallavis, & Haviland, 2009), and some autoethnographic studies have used this method of data collection when the author-researcher chooses to compose poetry as a means of data gathering and exploration (Fox, 2014; Gallardo, Furman, & Kulkarni, 2009). It is much more widespread for researchers to create transcription poems (Breheny, 2012), also referred to as data poems (Hordyk, Soltane, & Hanley, 2014; Lahman et al., 2010) or found poetry (Prendergast, 2009) from interviews or focus groups, using the participants' words, but representing them in poetic format. However, one qualitative study of young children's views of hospitalization did request composition of a poem specifically for the study—Carney et al. (2003) compared four formats for data gathering, one of which was an unstructured format asking children to compose a story or poem about their experiences. Although the unstructured format "often left the children wondering about what they could write" (Carney et al., 2003, p. 37), it simultaneously offered the benefits of allowing the participants to provide a true representation of what they considered most important (Carney et al., 2003).

My request for composition of a poem for this study was not without risk, since many people are intimidated by the idea of using poetry to shape and convey their thoughts, often due to unfamiliarity with the practice of writing poems. In order to mitigate and offset these risks, I included several options in the protocol. The most overt was my inclusion of an alternative to composing an original poem, and giving participants the opportunity to find a poem. Song lyrics were also offered as a source of poetic expression. To relieve anxiety about composing a poem, I emphasized the importance of meaning over format, and included instructions for writing some of the simpler forms of poetry such as *haiku* and *diamante*, while also providing examples of these types of poems. In a classroom study encouraging college students to explore mental illness through poetry, Chrisler (1992) obtained the best results by reassuring participants that content was more important than poetic format. I offered all these techniques in order to improve the participant's experiences with poetry, to enhance their personal reflections, and to enrich their interview.

Interview Phase

This was the centerpiece of the data-collection, and in this phase I relied on a detailed interview guide (Appendix F). The guide began with an introduction and overview of the study. Key elements of the overview included the purpose of the study, the conduct and duration of the interview, and an introduction of the researcher (Boyce & Neale, 2006). I provided assurances of confidentiality as well as opportunities for the participant to ask questions, and concluded the overview by obtaining informed consent and thanking the participant (Boyce & Neale, 2006).

Next, the protocol contained a tool for data collection, which was a combination of script and note-taking device. The script utilized a standardized open-ended interview guide format (Patton, 2002; Turner, 2010), sometimes referred to as a focused interview (Frankfort-Nachmias & Nachmias, 2008) or a semi-structured interview (Kvale, 2007). I selected this format in order to ensure that the basic research questions were covered, while simultaneously permitting exploration of emergent meanings (Patton, 2002), and allowing strong patterns in the data to unveil (Frankfort-Nachmias & Nachmias, 2008). My inspiration for the format was an instrument developed by Arcia and Fernandez (2003), which I used with permission (Appendix G).

I parsed the interview guide into categories that reflected the pre-coding I would be using for data analysis (Miles, Huberman, & Saldaña, 2014). Based on the research questions, common themes from the literature, and methodological considerations, I developed the questions and prompts, which were comprised of semi-structured and structured components (Kvale, 2007). Most of the structured questions were for the purpose of enabling the participant to quantify their response, while the majority of the semi-structured questions were designed to explore the participant's experience. I provide details of these types of questions in the next two sections.

The protocol continued with a discussion of the participant's poem, and then concluded with a debriefing segment (Kvale, 2007). This provided the participant with the opportunity for closure, by allowing them to deal with issues they may have been concerned about during the interview (Kvale, 2007). It also enabled me to use an important technique--asking the participant to suggest questions that were not asked, but that should have been included. This technique can provide valuable information that the researcher had not considered (Janesick, 2011; Patton, 2002). The final component of the debriefing allowed me to thank the interviewee for their participation.

Qualitative questions. A quality interview question should have two goals—to simultaneously provide worthwhile information, and also to foster a positive, interactive interview relationship (Kvale, 2007), so I crafted the qualitative questions for this study with this two-pronged objective of *thematic* and *dynamic* content in mind (Kvale, 2007). I commingled qualitative questions with quantitative questions, and progressed from being more dynamic to more thematic in order to build a foundation of trust and rapport (Jacob & Furgerson, 2012; Patton, 2002).

To enable the emergence of the phenomenon, the qualitative questions were open-ended, and the protocol incorporated a variety of Kvale's (2007) nine types of questions: introducing questions, follow up questions, probing questions, specifying questions, direct questions, indirect questions, structuring questions, silence, and interpreting questions. I designed the protocol to rely on my use of active listening (Kvale, 2007), and this semi-structured approach allowed me the flexibility to make extemporaneous revisions in order to pursue unexpected data during the interview (Jacob & Furgerson, 2012; Janesick, 2011; Kvale, 2007).

Quantitative questions. Since the gathering of quantitative data for this study augmented the qualitative strand, I interspersed closed-ended measurement questions at appropriate points throughout the interview protocol. The questions relied on nominal and ordinal levels of measurement to support the exploratory nature of the research and to help ascertain key associations between variables (Frankfort-Nachmias & Nachmias, 2008). Two question styles predominated—those involving rating and those focused on ranking (Frankfort-Nachmias & Nachmias, 2008).

I collected rating data using a 7-point scale that ranges from *not important* (1) to *moderately important* (4) to *extremely important* (7). The interview rating questions were always accompanied by a visual aid (Appendix H) consisting of a card with the numbers 1-7, the scale verbiage, and a series of 7 circles that progressed in size from smallest (1) to largest (7).

To measure the questions that involved ranking, I used a Likert scale format (Frankfort-Nachmias & Nachmias, 2008) by asking the survey respondent to rank order a series of factors in relation to each other. Then I used an open-ended question to inquire into the barriers (or facilitators) affecting parental perception, and I listed each factor named by the respondent on separate cards. I then displayed other cards with factors from the literature and pilot study, and asked the participant to rank order the factors from greatest impact to least impact. After I confirmed their ranking, I asked another open-ended question to explore their decision to order the factors in this manner.

Benefits and Disadvantages to This Protocol

Using a protocol that incorporates both structured and semi-structured questions offered several benefits. The standardized format contributed to a focused, efficient interview, and also facilitated data analysis (Patton, 2002), while the semi-structured questions encouraged an emerging approach. Articulating the questions in an interview guide format would also streamline the use of email interviews, should that contingency arise at the request of the participant (Creswell, 2013; Janesick, 2011; Patton, 2002).

The drawbacks to this approach revolved around the increased logistics (Creswell, 2013). I was prepared for dynamic and evolving situations, and was willing to juggle a variety of components during data collection. This might have resulted in my becoming overwhelmed (Creswell, 2013), which could have compromised the quality of the interviews. The best method to mitigate these obstacles was for me to thoroughly prepare for my role in advance.

Role of the Researcher

That the researcher will serve as the primary research instrument seems undisputed among qualitative scholars (Creswell, 2013; Janesick, 2011; Kvale, 2007; Miles, Huberman, & Saldaña, 2014; Patton, 2002). In my role as the central instrument for this study, I developed the research protocol, and then collected and analyzed the data. During data collection, I functioned as the interviewer, and was actively involved in eliciting the data (Creswell, 2013; Kvale, 2007; Patton, 2002). I took responsibility to develop my interviewing skills, and also to nurture a genuine interest in understanding other people's perspectives (Kvale, 2007; Patton, 2002).

A key element of my preparation for this phenomenological study was the process of *epoche* or *bracketing* (Creswell, 2013; Moustakas, 1994). This required me to recognize, identify, and then set aside my own experiences with the phenomenon, including any associated judgments or biases (Creswell, 2013; Moustakas, 1994). To suspend my prejudgment of the data (Patton, 2002), I fully articulated my experiences with the phenomenon, using journaling, narrative, and poetic styles of writing. Another technique I used to set aside my personal predispositions was the pre-coding of themes (Maxwell, 2013; Miles et al., 2014) into the data management system for the study, NVivo 10.

In part to hone my skills as an interviewer, as well as to ensure the quality of the interview protocol, I conducted both an instrument validation and a pilot study. Details of these proceedings are presented in the next section.

Protocol Validation and Pilot Study

I designed validation activities and a pilot study in order to highlight flaws or weaknesses in my protocol and provide me with opportunities to revise the procedures (Turner, 2010). The plan was to invite three research experts in the fields of psychology and qualitative methods to participate in a consensual validation exercise. These clinical experts would have agreed to serve as members of the consensual validation panel. The panel members would have been asked to review the interview protocol through participation in a telephone screening, a pre-interview reflection, and a face-to-face interview, either in person or via Skype. They would then provide comments on (a) the trustworthiness, validity, and scientific efficacy of the protocol, and (b) the interview skills and techniques demonstrated by the researcher. After synthesizing the various comments into the protocol, the pilot study was to be conducted.

Pilot study. The Walden University IRB [Approval #04-27-15-0352093] reviewed and approved the pilot study on April 27, 2015, and the detailed results are presented in Chapter 4.

Pilot and full study data retention. All raw data, including transcripts, original poems, notes, etc., will be held for a minimum of five years (Walden University, 2012). Paper forms have been placed in a locked file cabinet in my home, with the key available only to me. During the study and after completion, I stored electronic data on a password-protected external hard drive that I kept in the same locked cabinet when not in use.

Data Analysis Strategy

Qualitative Strand

Consistent with a phenomenological approach, I rooted the data analysis in the transcendental phenomenological model presented by Moustakas (1994). Then, in each of the four primary steps of the model--*epoche*, phenomenological reduction, imaginative variation, and synthesis (Moustakas, 1994; Patton, 2002)—I used poetry as one of the tools to augment the model, and enhance the effectiveness of the analysis (Janesick, 2011; McCulliss, 2013).

During the first step of *epoche*, I used the two techniques described previously for setting aside my predispositions (Moustakas, 1994) about the process of recognizing mental illness, including the composition of original and found poetry (Prendergast, 2009). In the second step of the model—phenomenological reduction—I began the process of coding the data from the interviews. After bracketing and subsequent use of each of the pre-coded themes, I commenced the process of *horizonalizing* themes (Moustakas, 1994). I used several open-coding techniques (Leech & Onwuegbuzie, 2007) to facilitate the emergence of a variety of themes. In order to accord each theme equal weight (Moustakas, 1994), I suspended judgment until I had completed an exhaustive review from multiple perspectives—in essence “moving around the statue” (Patton, 2002, p. 486). Some of the techniques I utilized were constant comparison (Leech & Onwuegbuzie, 2007), identifying metaphors and analogies (Gibbs & Taylor, 2005; Ryan & Bernard, 2003), key-words-in-context (Gibbs & Taylor, 2005; Leech & Onwuegbuzie, 2007; Ryan & Bernard, 2003), searching for missing information (Gibbs & Taylor, 2005), and indigenous categories or *in vivo* coding (Gibbs & Taylor, 2005). To capitalize on poetic inquiry, I also summarized and rewrote each interview in the form of a poem (Janesick, 2011; Mansell, 2013).

For the third step of imaginative variation, I began a systematic variation of ways to arrange or cluster the data, in order to recognize emergent themes (Moerer-Urdahl & Creswell, 2004; Moustakas, 1994). I used NVivo frequently during this phase to establish a series of hierarchies, and to capitalize on tools such as tag clouds and word frequency counts (QSR International, 2013) in order to regroup the data and utilize a fresh perspective. I also triangulated the data with poems from popular and cultural literature (Creswell, 2013; McCulliss, 2013). To culminate this step of the model, I wrote a textural description of *what* happened in the experiences, and a structural description of *how* the participants experienced the phenomenon (Moustakas, 1994; Patton, 2002). These two descriptions prepared me for the final step of the model—synthesis—in which I melded the two descriptions in order to describe the essence of the phenomenon (Moustakas, 1994; Patton, 2002).

Quantitative Strand and the Melding of the Two Approaches

My analysis for this study was an evolving process of data transformation, comprised of integrating and merging the qualitative and quantitative data (Creswell, 2009). In general, my strategy involved assessing the rich qualitative data first, to determine the themes and extract and quantify the factors. Then I analyzed the factors quantitatively to determine relationships and correlations. I used NVivo 10 software for the qualitative evaluation, and conducted the quantitative analyses using the Statistical Package for the Social Sciences (SPSS) software program, Student Version 21 software.

Employing a cross-sectional analysis, I examined the research subquestion: Which factors will significantly contribute to the percent variance change accounted for in parental problem recognition? The analysis for the hypothesis will be presented in null (O) and alternative (A) forms.

To examine the relationship between the independent variables of (a) normalization, (b) explanatory models, (c) stoicism, (d) stigma, (e) previous experience with mental illness, (f) social network, (g) media, (h) distress, (i) crisis, and (j) presence of a SBHC and parental problem recognition:

> $H1_O$: The independent variables of (a) normalization, (b) explanatory models, (c) stoicism, (d) stigma, (e) previous experience with mental illness, (f) social network, (g) media, (h) distress, (i) crisis, and (j) presence of a SBHC will not significantly contribute to the percent variance change accounted for in parental problem recognition of their child's mental illness.
>
> $H1_A$: The independent variables of (a) normalization, (b) explanatory models, (c) stoicism, (d) stigma, (e) previous experience with mental illness, (f) social network, (g) media, (h) distress, (i) crisis, and (j) presence of a SBHC will significantly contribute to the percent variance change accounted for in parental problem recognition of their child's mental illness.

I planned to use multiple regression analysis to evaluate the relationship between these variables. A higher ranking of an independent variable as affecting recognition (questions 5-9) would serve as the predictor variable. The length of time between initial awareness of a problem (question 3) and the decision that the problem was related to mental illness (question 4) would serve as the outcome variable.

Threats to Validity and Issues of Trustworthiness

Does this study measure what it purports to measure? This is the underlying concern of validity (Frankfort-Nachmias & Nachmias, 2008). Of the three types of validity—content, construct, and empirical—the most important for this study were content validity and construct validity. Construct validity poses the greatest challenge, since the construct of recognition is comprised of numerous behaviors, and a variety of variables impact a parent’s recognition. Careful attention to the definitions of the behaviors and their measures were necessary to enhance construct validity (Creswell, 2009). To heighten the content validity of the suitability of the instrument, I incorporated the results of the pilot study and comments from the instrument validation panel into the final research protocol (Frankfort-Nachmias & Nachmias, 2008).

Validation is a process wherein the researcher uses various procedures and standards to confirm the accuracy of their findings (Creswell, 2013). Since the methodological design of this study emphasized a qualitative approach, I relied on the criteria presented by Schwandt, Lincoln, and Guba (2007) that interpreted accuracy as the trustworthiness of a study. To ensure trustworthiness, a researcher must consider four criteria: credibility, dependability, confirmability, and transferability (Creswell, 2013; Schwandt, Lincoln, & Guba, 2007). Credibility reflects the participant’s perceptions of the *truth value* of the findings (Krefting, 1991). Dependability is also known as consistency, confirmability is synonymous with neutrality (Krefting, 1991), and transferability is analogous to generalizability (Creswell, 2013).

To ensure quality through these four criteria, I used tools such as member checking, triangulation, alternative themes, *epoche*, and rich description throughout appropriate phases of the study. Member checking was accomplished by using follow-up interviews as necessary to confirm findings or expand on conclusions. Triangulation involved my use of two or more data analysis tools to assess and confirm conclusions (Leech & Onwuegbuzie, 2007), and actively seeking out data that supported alternative themes can enhance confidence in the research findings (Patton, 2002).

Reflexivity, or the effect of the interviewer on the participant, was particularly important to the quality of this study since I had experienced the phenomenon being explored. Careful phrasing of the interview questions (Maxwell, 2013) and review of the protocol during the validation and pilot studies helped me to reduce bias in the questions. *Epoche* is a technique to identify and isolate personal biases, and in addition to the previously described actions taken in the data collection and analysis phases, discussing these biases in the final report can reduce suspicion about the potential influence of the researcher’s predispositions (Janesick, 2011; Patton, 2002). The final report further enhanced confidence in the findings through use of rich description (Creswell, 2013), and also by thoroughly detailing the methods and procedures, so that readers can ascertain the sequence (Miles et al., 2014) of data collection and analysis.

Despite these preparations, other impediments to quality might have developed during the study. I was prepared to address situations as they arose, especially those involving potential ethical concerns.

Protection of Participants

To protect the participants from harm or infringement of their human rights, this study received approval from the Institutional Review Board (IRB) of Walden University [Approval #04-27-15-0352093]. This study involved minimal risks when compared to the benefits; however, five areas of potential concern did exist—distress, unintended disclosure, intrusion of privacy, confidentiality (Walden University, 2010), and power dynamics (Creswell, 2013).

Although none of the participants were anticipated to be from a vulnerable or protected group, the possibility of distress due to recounting unpleasant and emotional memories might have occurred. During the interviews, participants might also have revealed confidential medical information about their child's diagnosis and treatment, and they might also have disclosed private information about their own medical conditions or their child's education, such as Individual Education Plans (IEPs) or disciplinary actions. Furthermore, participants might have divulged information about illegal acts such as drug use or abuse. To ensure the anonymity of the participants, I coded their names in letters, numbers, and symbols in order to prevent identification, and kept the original contact forms with the crosswalk information in a separate locked box in my office. In addition to precautions taken to ensure the anonymity of participants, I included each of these contingencies—distress, disclosure, and confidentiality—in the informed consent form, and obtained consent verbally and in writing at a minimum of two points in the protocol.

Since I was also serving as the interviewer, I remained aware of the asymmetric power dynamic (Kvale, 2006) that can affect the researcher-participant relationship, and I guarded against perceived manipulation, especially since the study offered compensation for participation. Additionally, I also weighed the risks of personal disclosure when establishing rapport, since sharing my own experiences could have influenced the quality of information that the participant contributed (Creswell, 2013).

Summary

The concurrent mixed methods approach for this study permitted me to explore the relationships and potential correlations between the various factors involved in parental recognition of their child’s mental illness. A transcendental phenomenological approach provided a trellis for my study, supporting use of a cross-sectional survey and poetic inquiry to triangulate and enhance the narrative data. By creating and pilot-testing a detailed and ethical interview protocol, I melded qualitative and quantitative approaches throughout each of the phases of data collection, analysis, and reporting. The themes and patterns that emerged as parents shared their experiences form the cornerstone of Chapter 4.

Chapter 4: Results

Introduction

Please Say the Word

Because I was voiceless, I became blind.
Because I was blind, I became distressed.
Because I was distressed, I became isolated.
Because I was isolated, I almost lost hope for my child.

But I heard you – glaring through my isolation – say THE word.

Because I heard you, I could name it.
Because I could name it, I could recognize.
Because I could recognize, I could change.
Because I could change, I found hope for my child.

(Researcher-created data poetry, inspired by the collective experience of the participants)

The objective of this concurrent mixed methods study was to investigate how Colorado parents learned to recognize their child's mental illness, and what affect school based health centers (SBHCs) had on their recognition process and initial decision to seek treatment. Using a convergent parallel design with a dominant qualitative strand, I sought to understand the variables that inhibited or enhanced parental recognition in order to help public administrators improve the responsiveness of mental health service policies and programs.

The following research questions and subquestions guided my exploration: How do parents describe their experiences of recognizing that their child's behaviors are related to a mental illness that requires treatment? To what extent does the presence of a school-based health center in the community affect parental recognition and initial treatment decisions?

1. Qualitative research subquestions.
    a) What impedes or enhances parents' perception and initial treatment decisions?
    b) How and why do parents overcome barriers to problem recognition?
2. A quantitative research subquestion.
    a) Which factors will significantly contribute to the percent variance change accounted for in parental problem recognition?

For the quantitative component, I used the following hypotheses to examine the relationship between the independent variables of (a) normalization, (b) explanatory models, (c) stoicism, (d) stigma, (e) previous experience with mental illness, (f) social network, (g) media, (h) distress, (i) crisis, and (j) presence of a SBHC and parental problem recognition:

$H1_{O}$: The independent variables of (a) normalization, (b) explanatory models, (c) stoicism, (d) stigma, (e) previous experience with mental illness, (f) social network, (g) media, (h) distress, (i) crisis, and (j) presence of a SBHC will not significantly contribute to the percent variance change accounted for in parental problem recognition of their child's mental illness.

$H1_{A}$: The independent variables of (a) normalization, (b) explanatory models, (c) stoicism, (d) stigma, (e) previous experience with mental illness, (f) social network, (g) media, (h) distress, (i) crisis, and (j) presence of a SBHC will significantly contribute to the percent variance change accounted for in parental problem recognition of their child's mental illness.

I begin this chapter by describing the changes I made to the instrument protocol as a result of the validation exercise and pilot study. Then I detail the data collection and analysis process and present the results by highlighting the three major themes and presenting descriptive and inferential analyses of the research findings. I conclude the chapter by explaining the strategies that I used to enhance trustworthiness.

Research Instrument and Procedure Modifications

Initial approval to conduct the research study was obtained from the Walden University IRB on April 27, 2015 (#04-27-15-0352093), and preparations were made to conduct both a validation exercise and a pilot study to verify the validity and reliability of the entire protocol before using it in the field. After discussions with my dissertation committee methodologist, I decided that to heighten the content and face validity of my study, it would be more valuable to obtain validation from field experts since the protocol had already been reviewed by subject matter scholars. Therefore, I invited four experts affiliated with SBHCs to participate in a consensual validation exercise.

Validation Exercise

Of the four SBHC staff who were invited, three agreed to serve as members of the consensual validation panel: The associate medical director of pediatric and adolescent services with the Metro Community Provider Network in Lakewood, Colorado, the director of youth and family services at Health Solutions in Pueblo, Colorado, and the director of community outreach with Kids First Health Care in Commerce City, Colorado. I provided the panel members with an overview of the study, and asked them to review the interview protocol via email in order to provide comments on the trustworthiness, validity, and efficacy of the protocol, specifically its suitability for use with the target population.

Each panel member offered written feedback on the protocol, as well as insights about the culture of the target population. Several examples of their comments are presented here. Three major themes emerged in their responses: Literacy concerns, the request for poetry, and interview logistics.

All of the panel members commented about some aspect of the literacy level, and recommended that the written survey be shortened. Two panel members specifically recommended a lower reading level and use of language that was less clinical. One panel member indicated the survey might be overwhelming due to its length and the request for a poem. Two members also expressed concern about the request for poetry, and one predicted a low response rate for this portion of the protocol. All of the panel members recommended that the written materials be translated into Spanish, and that I use an interpreter for the interview phase of the study. Two members suggested clarifying the concept and location of SBHCs. Panel members highlighted two issues regarding the conduct of the interviews. One panel member emphasized the importance of location, since many potential participants would have to walk to the interview. Another member highlighted a cultural norm to not show up for scheduled appointments, and urged me to consider ways to deal with this possibility.

After synthesizing the various comments from the panel, I made several changes to the protocol. I reviewed all of the language to ensure it was at or below a third-grade reading level, streamlined the advertisements, and shortened the written survey by truncating the request for a poem. Additionally, since the comment about the cultural norm to miss appointments raised concern, I reconsidered the compensation plan due to the drain on time and finances involved with interview non-attenders. The literature generally supported the idea that a token monetary incentive accompanying a survey could increase the return rate (Boucher, Gray, Leong, Sharples, & Horwath, 2015; Dykema et al., 2012; Griffin et al., 2011), due to "a sense of reciprocal obligation" (Dillman, 2007, p.153). Although none of these studies dealt with attendance at interviews, I was curious to see if a similar level of reciprocal obligation might be engendered. This prompted a request to the IRB for a change in compensation to include an additional two dollars provided with the advance survey at no obligation to the participant to attend the subsequent interview. Approval was granted on July 22, 2015.

I then obtained consensus from the panel members on the updated protocol (Appendices I, J, K, & L), had the documents translated into Spanish, made arrangements for an interpreter, and conducted the pilot study.

Pilot Study

I conducted the pilot study as a small-scale version of the main field study, in order to test the feasibility and efficacy of the processes (Arain, Campbell, Cooper, & Lancaster, 2010; Thabane et al., 2010), and to confirm the reliability and validity of the instrument and protocol with the target population (van Teijlingen & Hundley, 2001). Maintaining close consonance with the final study was also important, since pilot study samples might either be pooled with those of the field study if the key elements of the main study were maintained, (Thabane et al., 2010), or set aside and analyzed separately (Arain et al., 2010).

There is limited guidance on determining the sample size for a pilot study, although some scholars recommended obtaining approximately 10% of the final population size (Hertzog, 2008). Given this guidance and the hope that the data from the pilot study might be pooled with the field study if changes to the protocol were minimal, I planned the pilot study for between one and three participants, with a target of two.

The study was initially advertised according to the plan outlined in Chapter 3, and the specifics are presented in the next section. Two parents responded to the advertisements, met the qualifications, and agreed to participate in the study. Although unintentional, one of the respondents was an acquaintance of mine, so I maintained extra diligence to ensure her confidentiality and minimize researcher bias. I discuss this further in the section on trustworthiness.

The pilot participants confirmed the face validity of the protocol, indicating that it addressed the concepts it sought to measure, and also that the procedures were understandable, appropriate, and efficient. I subsequently aggregated the data from the pilot study (July 29-September 26, 2015) with the data from full study; the combined analysis and results are presented later in this chapter. Since no modifications were necessary for the protocol, I continued recruitment and data collection for the full study, commencing on September 27 and concluding on December 18, 2015.

Data Collection Process

Recruitment Approach

Although IRB approval had been obtained to advertise in three of the eight Colorado school district regions, the initial advertisement strategy involved circulating leaflets for the study in only the Metro and Pikes Peak Regions of Colorado (see Figure 3); I held advertising in the Northwest Region in abeyance due to travel cost considerations. The Metro Region contains eighteen school districts and twenty-five SBHCs in the Denver area, and the Pikes Peak Region is comprised of twenty-seven school districts with nine SBHCs in the areas surrounding Colorado Springs and Pueblo.

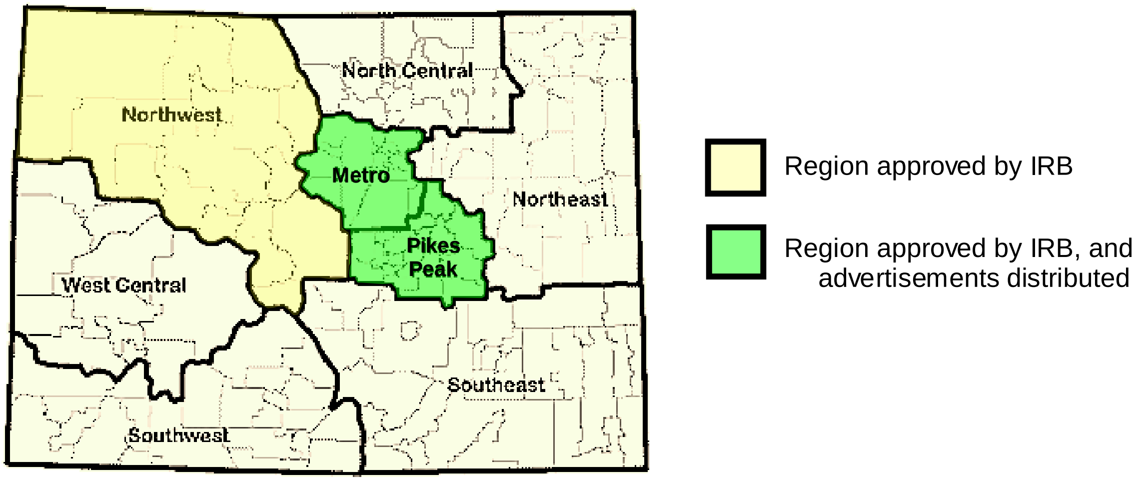

Figure 3. Colorado education regions approved for advertising for this study. Adapted from the Colorado Department of Education Region Information Map, retrieved from www.cde.state.co.us/cdeedserv/rgmapage.htm

Advertising began at the end of July 2015 in order to reach participants who met the study criteria: a caregiver responsible for making the medical treatment decisions for a child who had received an evaluation or diagnosis of a psychological disorder within the past year. At first, I distributed flyers to sixteen SBHCs in seven school districts.

Additionally, I asked well-situated people in the cities of Denver, Commerce City, Edgewater, Lakewood, Colorado Springs, Monument, Peyton, Falcon, Limon, and Pueblo—such as SBHC staff, mental health professionals, school counselors, and leaders of non-profit mental health support groups—to distribute pocket-sized advertisements and/or display full-page posters. However, because of the slow response to the advertisements after one month, I thus made an IRB request for two additional modifications to the study. The first was to expand the number of school districts in which advertisements were distributed from a maximum of twelve to a maximum of sixty-four, since mental health professionals who agreed to advertise the study served clients from a variety of school districts. The second modification was to increase the amount of time a caregiver had obtained the initial diagnosis for their child from one year to five years. I was granted IRB approval on September 9, 2015, and updated the screening questionnaire to reflect the change in protocol (Appendix M).

All of the research was conducted in 2015. Interviews began in August, and continued at approximately two-week intervals through the month of September. After the first three interviews, responses slowed in the month of October, so I expanded advertising efforts to include an additional school district in the Metro Region, Denver D-1, which contained 17 SBHCs. Ultimately, over a period of nearly 5 months (July-December, 2015), I contacted 88 professionals and volunteers in at least 15 school districts, and 46 agencies/individuals agreed to advertise. This resulted in a total of eight responses from prospective participants, six of whom qualified and agreed to participate, with five completing the study. I culminated data collection in December 2015 for four reasons: (a) the first semester was ending for holiday break in the public schools, (b) responses continued to dwindle, (c) the minimum number of participants had been interviewed, and (d) my resources were being stretched thin. Once I received approval from my committee, I requested that the remaining advertisements be pulled from all locations.

Demographic characteristics of participants. Despite the broad scope of the recruitment efforts, the participants were fairly homogeneous. All of the participants were the child's mother, and all indicated family income levels between $21,000 and $60,000 annually. The women all reported their ages between 41–60 years, and while all of the participants appeared to the researcher to be Caucasian, one identified "Hispanic or Latino" ethnicity on the written survey.

When comparing their prior experience with mental illness, all of the women indicated that they had at least a prior acquaintance with someone who had received a diagnosis of a mental illness, with the majority (n = 4) disclosing that this relationship had been with a close family member (parent, sibling, spouse, and/or child). In the course of the interviews, three of the mothers also revealed that they were personally receiving treatment for a disorder, and two referenced their other children (siblings of the subject child) who also had received a diagnosis and treatment.

The majority (n = 4) were from the Colorado Springs area, and one was from the Denver area. Although one prospective participant had responded from the Pueblo area, she did not meet the qualifications, since it had been 12 years since her child had been diagnosed. Another respondent lived in the Denver area, but she did not follow through with the interview. The five study participants lived in three different school districts (D-11, D-20, and Jefferson RE-1), but only one reported having access to a SBHC. Table 1 highlights the demographic differences between the participants, and also provides the pseudonyms by which each participant will be referenced throughout this dissertation.

Table 1

Demographic Differences Between Participants

Name [a]	Age	Race	# of Children	SBHC	School District	Family with Mental Illness	Self with Mental Illness	Children with Mental Illness
Lisa [b]	51-60	Hispanic	1	No	D-11	Yes	Yes	1
Amy [b]	51-60	White	2	No	D-11	Yes	Yes	1
Susan	41-50	White	2	No	D-20	No	No	1
Karen	51-60	White	7	Yes	Jefferson R-1	Yes	No	3
Debra	51-60	White	7	No	D-11	Yes	Yes	3

Notes. [a] For confidentiality purposes, pseudonyms are listed instead of participants' actual names.
[b] Pilot study participants

Settings. The face-to-face interviews were held in a variety of locations, each approved by the individual participant, following the plan presented in Chapter 3. I offered every participant the option of meeting at either a publicly accessible, semi-private location, or at an alternate location of their choice, to ensure their convenience, safety, and confidentiality. Three interviews were conducted in a semi-private office obtained by the researcher, one took place in the participant's home, and one was accomplished in the participant's office.

Data Collection

I collected the qualitative and quantitative data concurrently from each of the five participants, using the protocol refined during the validation exercise and pilot study. Prospective participants responded to the advertisements by telephoning either me or a Spanish translator who had signed a confidentiality agreement, and we determined eligibility by using the screening questionnaire (Appendix M). Each screening took less than 30 minutes, and if the caller met the study qualifications, a date, time, and tentative location were established, typically within two weeks of the screening. The screening call also provided us with the opportunity to establish an initial rapport, and to obtain their verbal agreement to participate in the study. After the phone call, I mailed each participant a printed survey pamphlet, along with the two-dollar token monetary incentive. A few days before each interview, one of us called the participant to confirm their receipt of the survey, to confirm the interview date, time, and location, and to answer any questions they had at that time.

Surveys. Each participant completed the survey pamphlet (Appendix K) at a time and location of their choosing, and brought their completed pamphlet and poem with them to the interview. Informed consent was obtained at two times—first by printing their name and the date when they first read the instructions, and again immediately prior to the interview, by signing and dating the survey along with the researcher. I provided a duplicate copy of the signed consent section prior to beginning the interview.

The written survey section captured demographic information that would subsequently be used for the quantitative analysis. Participants reported that they spent about five minutes completing this segment. After each interview, I entered the survey data into an Excel spreadsheet for storage until all interviews were complete. The survey pamphlet also included a request for a poem about recognizing mental illness, and the details about this form of data collection are presented later in this chapter. In the pamphlet, participants were asked to bring their poetry to the interview.

Interviews. All of the in-depth, open-ended, face-to-face interviews took place from August through November 2015. I conducted all of the interviews in English, even though a professional Spanish translator who had signed a confidentiality agreement was readily available.

Using the final interview guide (Appendix L) to provide a semi-structured approach, I began each interview by thanking the participant, providing a brief overview of the study's purpose, reviewing what they could expect including the risks involved, and confirming their consent to proceed. All of the participants gave their permission to video- and audio-record the interview. Using open-ended questions to establish a rapport, I then progressed to more thematic content by encouraging each participant to tell me their story of recognition. This gave them control of the interview; however, when necessary I would probe beyond their narrative of *what* happened, to explore the details and emotions of *how* they perceived the experience.

Structured quantitative questions with ratings were interspersed throughout the interview, to augment and triangulate the qualitative questions. As a means of probing and encouraging their recollections, we "play[ed] a card game" (Lisa [pseudonym], personal communication, August 29, 2015)—a phrase coined during the pilot study—at several points during the interview. I had printed out small cards, each with a different quantitative variable related to the process of recognition. Additionally I created cards on the spot if they introduced a factor that was not included in the list—for example, one participant insisted that “red dye” (Karen [pseudonym], personal communication, October 17, 2015) in foods had created a significant barrier to her recognition, so we wrote a card for red dye/foods. Each *card game* involved asking the participant to consider all of the cards/factors, and then rank them in priority order, with the most important factor at the top, the least important at the bottom, and those that did not affect their recognition off to the side. I then asked the participant to tell me why they put the cards in that order, which not only gave me a quantitative ranking, but also elicited rich qualitative responses about each of the factors and their relationship to each other. The *card games* were used at two points in the interview—when discussing the barriers to their recognition, when exploring the things that enhanced their recognition. We then referred back to their rankings when considering the things that helped them overcome the barriers to recognition.

I used a second type of *card game* to elicit quantitative rankings on the relative importance of different variables in the recognition process. This device used a single card (shown at the end of Appendix L) comprised of a numeric and graphic Likert scale. I asked each participant to point to the ranking that showed the relative importance of each factor considered. This technique triangulated the quantitative and qualitative responses, providing the opportunity to explore the deeper meanings behind the numeric rankings.

The numeric rankings also triangulated and quantified narratives that had occurred earlier in the interview.

The interviews culminated with the opportunity for the participant to suggest questions that I had not asked, to ensure that their recognition experience had been thoroughly explored. After thanking them for their participation, I offered the promised compensation, which was declined by two of the mothers. The unused gift cards were donated to a local chapter of the Depression and Bipolar Support Alliance.

Field notes were written in each interview guide during the interview, and I included my overall perceptions in my journal after each interview, and again after reviewing the video recordings. I transcribed each audio recording verbatim, saved it in a Word document on a password-protected drive, and then saved a redacted copy on my personal computer. The quantitative elements were extracted from the field notes and confirmed with the transcript, and then entered into the Excel spreadsheet.

Three unanticipated situations occurred during data collection— two that I considered assets, and one that proved to be a disadvantage. The first situation occurred when two of my friends/acquaintances responded to the advertisements, and subsequently qualified for the study. As described in the section on trustworthiness, this required extra diligence on my part, but produced unexpected benefits in increased candor about the effectiveness of my pilot protocol, and extra conscientiousness when safeguarding the privacy of participants' identities and the interview transcripts. The situation that was an unanticipated drawback was that only one of the participants had access to a SBHC. This required me to modify or even skip questions during the majority of the interviews, typically eliminating those questions pertaining to SBHCs. Although the interview guide facilitated these truncations, I had not foreseen having to essentially eliminate this variable from my research. Conversely, I had expected a great deal of resistance to my requests for poetry, and was therefore pleasantly surprised by the third unanticipated situation, when all of the participants agreed to provide a poem as part of the data collection.

Poetry collection. The request for a poem was included as part of the pre-interview survey pamphlet (Appendix K). Participants had the option of either composing or finding a poem or song about the emotions they experienced when recognizing their child's mental illness. No format or length was suggested—a change from the plan in Chapter 3 (Appendix E)—due to inputs from the validation exercise. However, I did emphasize that the poem should be meaningful to them. Eventually, everyone provided a poem. The majority (*n* = 4) of the participants brought the poem and read it during their interview, and the fifth participant e-mailed me her poem after the interview. Two of the mothers indicated that they spent an hour or less finding a poem that spoke to their recognition experience, while three mothers spent significantly more time composing original works. Two of these mothers shared their poems with some of their children before or after the interview, with the other stating that she intended to offer her poem as a gift to her daughter.

The data from the poems were recorded in several ways. First, four of the poems were read, and video- and audio-recorded during the interviews, and then each was typed as part of the interview transcript. The fifth participant e-mailed her poem, and included some additional thoughts about her composition. These techniques enabled me to capture the participants' commentary and insights, in addition to their poetry. Further, all five poems were input into separate Word documents, with careful attention to replicating the original format. This allowed me to analyze the data from the poems separately from the other data components, when desired.

Data Analysis Process

The mixing of methodologies assumed increased prominence during the analysis phase, as I embarked on a process of data transformation that enabled the emergence of major themes. I used the four steps of Moustakas' (1994) transcendental phenomenological model as the framework for the data analysis process. During each step—*epoche*, phenomenological reduction, imaginative variation, and synthesis (Moustakas, 1994; Patton, 2002)—I used an iterative process of melding, unmerging, and triangulating the qualitative data with the quantitative data and a variety of poems.

Step One: Epoche

The initial step of *epoche* proved doubly important, when during the course of this study, a second of my children received a diagnosis. Thus I felt compelled to set aside my preconceptions about the research phenomenon not once, but twice. I accomplished *epoche* by running myself through the entire protocol, thoroughly considering my responses to each question, and using the technique of journaling to process through difficult barriers. I also composed poems about my own experiences in recognizing my children's mental illnesses, and rigorously confronted my own predispositions, expectations, and issues, in order to be prepared to bracket out and overcome them during the data gathering and analysis.

Step Two: Phenomenological Reduction

The process of transcribing each interview and conducting a thorough review of the audio and video recordings with the transcripts gave me the opportunity to delve into each individual's experience, and also to begin to gather "a sense of the whole" (Giorgi & Giorgi, 2003, p. 251). In order to thoroughly understand each lived experience, I used both the quantitative and qualitative data to depict a graphic timeline of the awareness and recognition milestones for each experience. Additionally, for each interview, I developed individual textural descriptions of specifically *what* happened, and structural descriptions of *how* the participants each felt during their experiences. I then filed the timelines and descriptions for later use, and turned my attention to coding the data.

Coding. Using NVivo 10 software, I began entering the data using pre-coded categories (nodes) based on the interview guide, in order to further bracket and set aside preconceptions (Patton, 2002). This deductive style also facilitated a distillation of the transcripts, which laid the groundwork for subsequent poetry composition. The pre-coded data set was then held in reserve, and I suspended judgment while creating a new set of nodes using an inductive system of open coding and constant comparison (Leech & Onwuegbuzie, 2007) to enable themes to emerge. Since the search for semantic relationships was an integral component of this step of phenomenological reduction, I began utilizing poetic inquiry techniques, in conjunction with the coding process.

Poetic inquiry. After coding each of the participant's poems into a node, I then began composing both original and found poetry. The technique of writing *found poetry* (Prendergast, 2009), also known as data poems or transcription poems, involves the researcher using or representing the participants' words in poetic format. For each interview, I composed between two and five poems, at least one of which met the criterion for found poetry. I challenged myself to experiment with a variety of poetic formats, in the belief that changing the format would change my thought processes about the information, and potentially reveal a new perspective. Sometimes a participant's word choice would spark use of a rhyme- or repetition-based format such as a *triolet,* or the cadence in their voice during the interview would suggest a rhythm-based or syllable-count format, or a particularly haunting theme might call for a more traditional form such as a *cinquain* or a *haiku.* Often the most rudimentary poetry formats, such as the *diamante,* could reveal important insights, due to the distillation and polarity of thought required by the form's internal transition.

Forcing myself to adhere to a chosen poetic format typically resulted in new ways to "fracture" (Maxwell, 2013, p. 107) and rearrange the data. Figure 4 offers a contrast between two poetic formats used to explore a single experience. In this example, Susan described her recognition experience as one of "lost hope and found hope" (personal communication, October 1, 2015), and she recounted reaching a crisis point when her daughter began mutilating herself, and was subsequently hospitalized. When researching synonyms for *hope*, I came across the word *sanguine,* and was struck with the similarity between that and the word *sanguinary,* which has to do with blood—a word Susan had used in the interview. Placing these two words in opposition at the top and bottom of the diamante format resulted in insights about a transition to recognition that were substantially different from those that emerged from the second poetic process, which explored lost and found hope by capitalizing on both rhyme and a syllabic pattern of 6-5-5-5-6.

Diamante Format	*Rhyme & Syllabic Patterns*
Transformation Journey Sanguinary Blood Rage Cutting Failing Devastating Isolated Hopeless Named Cautious Seeking Praying Healing Community Music Sanguine	The Blind Spot for teen angst mistaken her childhood taken all hope forsaken my faith unshaken now hope reawaken!

Figure 4. Contrasting poetic formats. Examples of the insights obtained when using different poetic formats.

In addition to composing found poetry from the interview transcripts, I also coded and triangulated the participants' poems with their interview narratives and their quantitative inputs. Another poetic inquiry technique was to search the cultural literature for poems suggested by comments or themes within each interview, and incorporate those insights into the coding. This back-and-forth process of fracturing and comparing the data led gradually into the third step of the data analysis model.

Step Three: Imaginative Variation

The purpose of this step was to examine the data from a variety of perspectives in order to expand upon or enhance the emerging themes (Patton, 2002), so it was at this point that I began focusing on the quantitative data.

Quantitative analysis. The information gleaned from the surveys and transcripts was transferred to the Statistical Package for the Social Sciences (SPSS) 10 software. Unfortunately, the sample size was too small to meet the data assumptions required for prediction in the multiple linear regression analysis, so I was forced to modify the quantitative analysis plan described in Chapter 3, abandoning the cross-sectional analysis in favor of a relationship analysis. Using SPSS to run frequency distributions, and these tables revealed relationships in the data, specifically patterns and contrasts between the participants' responses. The frequency distribution tables served as a whetstone for inquiry on the emerging themes, highlighting some interesting disjunctions between the individual experiences, and revealing outliers and discrepant elements in the phenomenon. I continued to triangulate back and forth between the quantitative and qualitative data in the process of data transformation.

Data transformation. As a result of the quantitative analysis, and as a means of exploring the discrepant elements, I went back into NVivo and created a third set of nodes, organized by the research questions. This fragmented the data based on the independent variables, and helped me consider two new groupings: (a) what I found that I did not expect, and (b) what I had expected to find, but did not.

Based on this new triangulation, I decided to add extra variables to the SPSS database, using insights from my field notes on the independent variables, and I ran new frequency distributions. This constant, reiterative, and recursive process of triangulation between quantitative, qualitative, and poetic analyses—between inductive and deductive analyses—resulted in clarification of the emerging themes, so I created a framework of nodes in NVivo to organize the data according to nine initial invariant themes. This axial coding enabled me to make connections between the categories established during pre-coding and open coding, and resulted in "horizonalized" (Patton, 2002, p.486) data, where all the codes were given equal significance.

The following example illustrates how this reiterative triangulation process contributed to theme development. Lisa had indicated that attributing her child's behaviors to the stress of an impending divorce had been a significant barrier to her recognition process. Her comment, "I realize that I was in this cloud of not noticing, and I bet there's a lot of people who are in that cloud, you know, for some reason or another" was initially coded at an invariant theme node called *Life Clouds Recognition*, which was subsequently incorporated into the emerging theme of *Clouds Get in the Way*. After examining the SPSS frequency distribution tables, I observed the pattern that all of the participants had selected *Thought It Was Normal / Child Would Outgrow It* as one of their top five barriers to recognition. Upon further consideration of the number of qualitative and poetic references to other explanatory models and the descriptions of distress, the experience of *clouding* was incorporated into the final theme of *It Must Be Normal, So I Should Keep Handling It.*

To culminate the data reduction (Miles, Huberman, & Saldaña, 2014) in this step of the model, I began consolidation of the textural and structural descriptions. To this end, I used selective coding to elucidate the core themes, by subordinating or deleting nodes. Continued triangulation helped me consider the relative importance of frequency counts, graphic displays of semantic relationships such as word trees and tag clouds (QSR International, 2013), and the intuitive sense I had gained by immersing myself in the data. After composing a final draft of the consolidated description, I allowed these discoveries to incubate over several days, heightening my receptivity to any further insights, and ensuring that the themes and description would stand this small test of time before I progressed to the final step of the analysis model.

Step Four: Synthesis

During the incubation, I composed more poems about the collective experience of these participants. To enhance the trustworthiness of my results, I also reviewed my own experiences, to ensure I had sufficiently bracketed out or reconciled any similarities to the participants' lived experiences. Ultimately, a few minor refinements were necessary to fully blend the textural and structural descriptions, thus crystalizing three themes that were crucial to understanding these women's shared phenomenon of recognizing their child's mental illness (Creswell, 2013). Had any of these themes been absent, the essence of the experience would have been lost.

Results

This study was originally designed to be guided by two main research questions and three subquestions; unfortunately, two of these five questions had to be abandoned due to lack of data for meaningful analyses. Table 2 displays the disposition of each research question, and the rationale for the decisions to discard specific questions. The discussion in this section is organized by the three remaining research questions. Themes and correlations will be interwoven throughout the discussion, supported by direct quotations from the participants to provide rich detail and validation. I offer an interpretation of these results in Chapter 5.

Table 2

Reasons for Discarded Research Questions

Research Questions	Disposition & Reasons
RQ1: How do parents describe their experiences of recognizing that their child's behaviors are related to a mental illness that requires treatment?	Retained.
RQ 2: To what extent does the presence of a school-based health center in the community affect parental recognition and initial treatment decisions?	Discarded. Only 1 participant had access to a SBHC, so these questions were eliminated from 4 of the 5 the interviews.
Qual SubQ1: What impedes or enhances parents' perception and initial treatment decisions?	Retained.
Qual SubQ2: How and why do parents overcome barriers to problem recognition?	Retained.
Quant SubQ3: Which factors will significantly contribute to the percent variance change accounted for in parental problem recognition?	Discarded. Since there were only 5 participants, the sample size was too small for a meaningful prediction. Instead, a frequency analysis was used to quantitatively explore and triangulate the qualitative themes.

Research Question 1

How do parents describe their experiences of recognizing that their child's behaviors are related to a mental illness that requires treatment? Exploration of this overarching research question resulted in the emergence of three essential themes: (a) because it's your kid, (b) it must be normal, because I can still deal with it, and (c) in a word … validation.

Theme 1 – because it's your kid. The title for this theme jumped onto the page when three of the mothers used a nearly identical phrase, at nearly the same point in the interview—almost as if it were a rallying cry. This theme encompasses two important aspects of the Colorado mothers' recognition experience: (a) the self-esteem they derived from being a parent, and (b) feelings of guilt about not recognizing sooner and/or having to let go as their child healed.

Despite the challenges of dealing with a child with a diagnosis, all of the mothers derived a great deal of self-esteem from being a good parent, and helping their child deal with their challenges. Debra (personal communication, November 15, 2015) speaks of her determination to find help for her son, "…there wasn't somebody out there that would come to us and say, hey, this is what's going on. I was going to have to push and seek and, and find the answers for my family."

Perhaps it was because their self-esteem was related to being an effective parent that the mothers expressed a sense of guilt at either not recognizing, or perhaps in some way having caused or exacerbated their child's condition. Susan did not recognize her child's behaviors as related to mental illness until after a crisis required her daughter's hospitalization. She remembered her guilt being compounded by other extreme emotions, and thus feeling:

> Like I was the worst parent in the world! Yeah, it really did. It really, it was really devastating. Um, I was scared, all the time. All the time. Um, knowing she was in the hospital, it was, uh, you know, I knew she was getting good care, but, and I knew I couldn't provide the care that she needed, the help, so, yeah. It was hard not to see, I'm used to seeing my kids every day, so, um, that was really hard. Yeah, um, and it's hard to know that your child is hurting that bad, and there's really nothing you can do.

Two of the mothers felt especially guilty about not recognizing the signs and symptoms sooner, since they had experience with mental illness in a close family member. Lisa expresses this in several stanzas of her poem, along with an echoed reminder to her daughter:

> If I had remembered
> That it was such a part of your family tree
> I would have started sooner
> Caring for your mental health
>
> We always loved you
>
> [stanza omitted]
>
> Yet somewhere along the way
> I lost track of my own mind
> They said it can happen for a parent
> At a time when I became lost as a child
>
> We always loved you
>
> [stanza omitted]
>
> And I knew how lost you could become
> But there was nothing more I could do
> And you began to slip
> As far away as you needed to go

And we heard you
And saw your sadness
And I knew someone could help you
Even if it couldn't be me

We always loved you

Research Subquestion 1

What impedes or enhances parents' perception and initial treatment decisions? In answering the first part of this question, which deals with impediments to recognition, the second theme provided the most valuable insights. And while there was no cogent theme related to the second half of the question—things that enhanced parental recognition—there were nonetheless some interesting patterns and correlations that are worthy of comment.

Theme 2 – it must be normal, so I should keep handling it. The most palpable barrier to these mothers' recognition was their perception that that child's behaviors were attributable to either a normal developmental phase, and/or to a stressful event in their environment. Since they framed the problem as something that would be outgrown, or that was typical to the experience of parenting, they would reason that it was something that they could overcome or wait out—certainly it was something they thought they could handle, despite their rising levels of distress and/or worry. As Debra explained, "So, I didn't think it was serious enough yet, um, which would then mean that the child would outgrow it." Susan recalls that,

> …she was not bathing as often, which we thought it was normal teenage stuff, um, a lot of isolation, staying in her room a lot, um. She was coming home with some injuries, um, first on her hands, that said, she said it was from a game they

> were playing at school, um, but then was coming home with marks on her arms, first on the upper arms, "Oh mom, I scraped a tree." … Um, but like I said, it was easier to recognize it, after the fact, then before…

Two mothers explained how easy it was to find plausible explanations not only for their children's behaviors, but their own distress. Lisa described a combination of a stressful event and hormonal changes as her assessment of the cause of her daughter's change in behavior:

> …[her] father and I um, uh, separated, and from the time that we separated, um for, um well after about a year, um she started to really withdraw, and so for about three years she withdrew to the point of, um, not hugging with me, not talking to me, um, and I could see the distance, so um, during that time I too was doing my own healing process, so, it took me a while to, um, address it? I would say? …and what I perceived initially as puberty, early onset of puberty. I mean she was 10, 11, and it seemed kind of early but maybe not, um, compounded by this parent separation thing…

And Karen shared several different things that appeared to explain her son's behaviors, but in reality were masking the problem:

- …when he was four we transitioned from Arizona to here. I mean nothing is more stressful in life than divorces, marriages, and moving.
- But the red dye, when he ate foods, or drank stuff, that seemed to have that, oh the behavior was worse…

- …very active…. Yes. Very active. And because kids are excited, and they just came from school, and they want their snack, and they're doing this and that, oh the confusion, just escalated [his] behaviors. Yeah. Yes, it did. He likes quiet, and structure … he works well like that. Um, but without that, at the daycare center, yeah, things were a little bit unruly.
- Oh, and a lot of times we do think, oh that's normal, all that rambunctiousness, and ants in the pants…

Patterns and correlations in barriers and facilitators. Examining the frequency distribution tables for the purpose of triangulation revealed some correlational patterns, which augmented this theme. One pattern was the ranking of barriers to recognition. All of the participants selected the card "thought it was normal/child would outgrow it" as one of their top five impediments, four of the mothers selected an environmental attribution as one of their top five obstacles, and three selected the card "didn't think it was serious enough yet" as one of their top two barriers to recognition.

There were some interesting patterns in what the participants did *not* select as having an impact on their recognition. Despite all of the participants being in the lower- to middle-income bracket, none indicated any barriers due to lack of insurance or the cost or accessibility of services. And it surprised me that no one ranked the media, including TV, as helping or hindering their recognition process, although Amy (personal communication, September 17, 2015) expressed concern in the interview about the potentially negative consequences of media reports that children's behaviors are overly medicalized:

> The media, I'm a little troubled by, you know, all these… you know, you, you go through this, you make a choice, it's working, yet you have to defend that choice, because everybody's all like, "well, children are on too much medication", you know, "the educational system isn't designed for boys", "no it is, and we're holding girls back" and I, I don't know.

However, the most prominent correlational pattern revealed by the frequency distribution analysis was the importance that all of the participants placed on their prior experience with mental illness. The four mothers who had a prior close relationship with someone who had a mental illness all selected this experience as one of their top three facilitators to recognition, and the one mother who did not have prior experience listed this lack as her top barrier to recognition. To explore this pattern more thoroughly, I ran a Spearman's rank-order correlation to determine the relationship between the five mothers' close prior experience with mental illness and the outcome variable of length of time to recognition.

There was a moderately strong, negative correlation between prior experience as a help to recognition and the length of time to recognition, which was not statistically significant ($r_s(8) = -.649$, $p = .236$). There was a strong, positive correlation between no prior experience as a hindrance and the length of time to recognition, which was not statistically significant ($r_s(8) = .745$, $p = .148$). Finally, there was a very strong, negative correlation between prior experience as a benefit to overcoming barriers and the length of time to recognition, which was statistically significant at the 0.05 level ($r_s(8) = -.913$, $p = .030$). Scatter plot diagrams were then created for each of these variables, and confirmed the strength of the relationship with only two of the variables: helped recognition, and hindered recognition. A comparison of the results from these three correlations is displayed at Table 3.

Table 3

Correlations with the Outcome Variable (Length of Time to Recognition)

Variable	Correlation	P value	Strength Confirmed
Prior experience with mental illness helped recognition	$r_s(8) = -0.649$ (decreased time to recognition)	$p = 0.236$	Yes
No prior experience with mental illness inhibited recognition	$r_s(8) = 0.745$ (increased time to recognition)	$p = 0.148$	Yes
Prior experience with mental illness helped overcome barriers to recognition	$r_s(8) = -0\ .913$ (decreased time to recognition)	$p = 0.030$	No

A variation of this pattern emerged when comparing the level of each mothers' distress before recognition occurred. Two of the mothers (Amy and Debra)—each who had a prior close experience—described low to moderate distress before recognition, two (Lisa and Karen)—who also had a prior close experience—described medium to high levels of distress, and one mother (Susan)—who had no prior close experience—described reaching a crisis point prior to recognition. It was interesting to compare Susan's experience of reaching crisis with Debra's description of the recognition process for her first child, an elder sibling of the subject child in her interview. Debra's narrative about her first recognition experience closely paralleled Susan's story, in terms of a significantly extended period of time culminating in a crisis.

When examining the relationship between the variable of *prior experience with mental illness* and the outcome variable of *time between awareness and recognition*, the correlational pattern continued. Again, the four participants who had a prior close relationship had shorter recognition timelines than the one participant with no prior close experience. This particular pattern was echoed and strengthened by the narratives of the two mothers who had older children with a diagnosis. The period to recognition for their first child was much longer, and much more distressful, than the recognition time for their younger (subject) child, and the length of time for the first child was similar to that of Susan, with no close prior experience. A comparison of the recognition timelines for each child, as described by the participants, is shown in Figure 5.

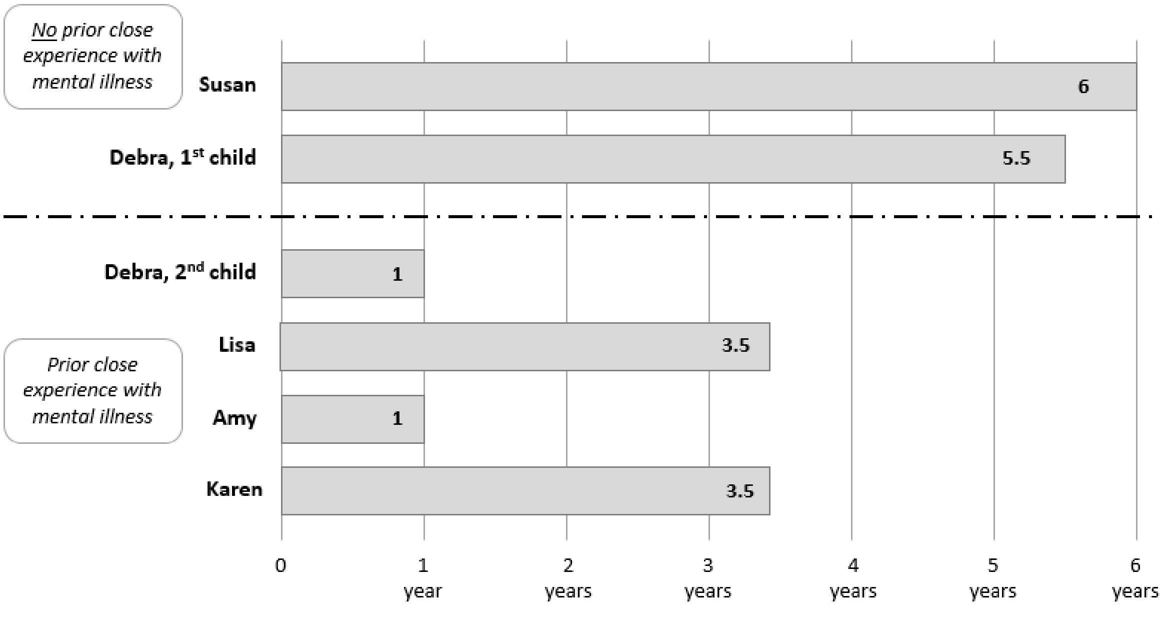

Figure 5. Time (in years) from initial awareness to recognition, and the relationship of a prior close experience with mental illness. Estimates based on mothers' narratives.

The qualitative data confirmed that across every timeline, each participant acknowledged some level of self-deception and/or avoidance throughout their recognition experience. Although this finding may have been exacerbated by the hindsight inherent in the retrospective nature of the interview process, all of the mothers indicated that during their recognition journey they were cognizant—at some level—that they were putting off dealing with something more serious:

> Lisa: I think there was kind of a short period of…like hanging on to normalcy, like denial, or whatever…
>
> Debra: It's normal, he's under a lot of stress, you know, that sort of thing…
>
> Susan: Um, we had seen, some things that were worrisome, but I don't know if we had our heads in the sand, or just didn't know.
>
> Amy: I think we would have lollygagged along.
>
> Karen: …so, self-denial really got in the way a lot I think, you know, making excuses, you know…

This deferring or putting off was present to some degree in all of the Colorado mothers' experiences, despite varying levels of awareness, or even watchfulness. Amy, herself diagnosed with dyslexia, describes being "attuned to [her son's] difficulties" (personal communication, September 17, 2015), with a rising concern that he might also be dyslexic. Yet despite her high level of awareness, she—and all of the mothers in this study—seemed to need help climbing over an apparent barrier to their recognition.

Research Subquestion 2

How and why do parents overcome barriers to problem recognition? The aspects of intuition and the importance of a social network surfaced as prominent components of the lived experience. In order to move from awareness to recognition, the mothers needed some sort of confirmation in order to validate their growing concerns, or give a name to their distress.

Theme 3: In a word …validation. The title for this theme was drawn from the frequent mention of words dealing with voicing, naming, or hearing specific words. It was as if the mothers felt voiceless, or needed the empowerment that came from being able to name their distress.

Three of the women referred to a guiding voice or intuition. Debra recounted, “And so, my internal voice was telling me, ‘OK what [my son] is saying goes beyond some of my misgivings, or my hesitations, or my [pause],’ so, yeah.” Susan’s intuitive sense was connected to her faith, “…that was a higher, you know, it was God telling me, you need to watch your child, because she’s exhibiting signs... When God gives us that intuition to know when our kids aren’t quite right; you just gotta listen…” And Karen went through a process of denying her intuition until it became too compelling:

> We are the first ones to, to say, “Hmm. Something’s a little off here.” You know. We’re also the first ones to dismiss all that. You know, and um, but, but we see it, and it’s a red flag, and we know it. You know, and maybe we’re not paying attention to the red flag, until there’s six, or seven, ten red flags. Then we say, “Hoo wee. I gotta fix this, I gotta do something.”

The importance of hearing explicit words—something that connoted diagnosis or need for treatment—was evident in all of the interviews. In some cases it was a naming or re-naming of the behaviors, and in some experiences it was confirmation of suspicions or concerns. Lisa remembered the experience of hearing someone saying a specific word as “Glaring! Like oooooh!” adding,

> So, when that doctor said the word “depression”… I know about depression, and I have had depression, and have depression, you know, I mean I’m familiar with this, but to hear a doctor say it, which is what why it, you know I realize that I was in this cloud of not noticing…

Debra heard the words directly from her son: “He actually had come to me and said, ‘I think I need to see somebody,’ and I said, ‘OK, what’s going on, talk to me.’” For Amy the call came from her son’s teacher, asking to set up a meeting to discuss the school’s concerns,

> I was aware that he had some problems, with like, speech and his handwriting, but then his 1st grade teacher called and she was like, “Don’t freak out,” and I’m like, “Well, you know, I’m gonna freak out”, but then it was like, “this is what’s going on…”

Susan described the importance of hearing an accurate diagnosis, “So, having a professional that knew what the heck they were doing, um, really helped, uh, with the diag… [*sic*] having an official diagnosis helped, overcome, a lot of these things.” And Karen received repeated calls from the school staff about her son’s behaviors, and then heard her son express his feelings of low self-esteem. She wept during our interview as she recalled, “Um, he just thought that he was, um, a bad kid. And that’s not the case.”

The mothers’ social networks not only helped galvanize them to recognition and treatment seeking, but provided a high level of support after recognition. Gratitude for the help they received from their friends, family, teachers, and mental health professionals was expressed frequently, yet was in sharp contrast to their described feelings of isolation and distress during the recognition process. When asked what advice they would offer to other parents in a similar situation, these participants unanimously recommended reaching out to others.

> Amy: I would say, educate yourself, um, through friends, through the internet, through books…
>
> Debra: I would encourage you to talk about what you're experiencing, what you're feeling, what you were witnessing.
>
> Karen: …my thing to them would be, go see somebody. Go see ***somebody*** (emphasis added to reflect Karen's vocal intonation). There's a lot of places out there that can help you with that.
>
> Lisa: Who can we connect you with, to, you know, can I help you? Or, who would you feel comfortable talking to…that's what I would ask them.
>
> Susan: The first thing I want you to know is, that I wish someone had told me, is you are not alone. Um, this is not just one person. It's, your child is not the only one and you are not the only mom that's going through it."

Evidence of Trustworthiness

Trustworthiness requires rigor to ensure the validity, or accuracy, of the study results. The level of trustworthiness can be measured by considering four criteria—credibility, dependability, confirmability, and transferability (Creswell, 2013; Schwandt, Lincoln, & Guba, 2007).

To enhance the credibility of the results I implemented the strategies presented in Chapter 3, the most prominent of which was inculcating triangulation throughout the entire study, from conceptualization through data collection, analysis, and interpretation. Conducting both a validation exercise and a pilot study enabled use of outside experts and member checking to ensure the face validity of the interview protocol. In this chapter, I capitalized on quotes from participants to support the findings. I also reported a systematic analysis process that sought a variety of divergent patterns, rival explanations, and negative cases during the discovery of the themes. The most unexpected challenge to credibility arose when two friends/acquaintances responded to the study advertisements. Since my office was in my home, I took extra precautions to partition the data from my family, thus protecting the participants' privacy and that of their children, who were friends of my children. Beyond the planned procedures of redacting the transcripts and password-protecting and locking up the data, the participants and I agreed upon use of fake names whenever we were talking on the telephone, in case my children were able to hear me during the screening calls, and I also used headphones if I needed to listen to the interview recordings when my family was at home while I was working.

Dependability, or consistency, was maintained by keeping field notes and journals, and using an interview guide to maintain as much consistency as possible between all of the interviews. I video- and audio-recorded each interview, which provided a reliable, retrievable account of the participants' exact words, vocal inflections, and body language. During the data analysis phase, Moustakas' (1994) transcendental phenomenological model served as a framework and touchstone, helping me regulate and stabilize my investigation through use of a proven process.

Confirmability—analogous to neutrality or objectivity—was pursued through the processes of *epoche,* bracketing, and journaling, and enhanced by the expert reviews during the validation exercise. This component of trustworthiness presented the greatest challenges due to my personal experiences with the study phenomenon. To reduce researcher bias and the potential for reflexivity during the interviews, I engaged in an additional process of *epoche* and bracketing beyond what I had outlined in Chapter 3, to ensure I could remain objective when recognizing the need for my second child's diagnosis.

Throughout the study's conceptualization, I recognized that transferability and generalizability would be significantly limited, due to the predominance of a phenomenological methodology and the small sample size. To offset this, I planned to recruit a heterogeneous population from a variety of locations around the state of Colorado; unfortunately I was unsuccessful in these attempts. The one strategy I was able to implement was the use of thick description of the phenomenon, so that readers can evaluate whether the results of this study could be transferable to other contexts.

Summary of Findings

In this chapter, I presented the process used to obtain the results of this study. After describing the conduct and outcome of both the validation exercise and the pilot study, I provided details on the data collection and the data analysis. The results were organized by the themes and patterns that emerged from an exploration of the research questions, and the chapter concluded by providing evidence of trustworthiness.

Although this study began as an investigation into how Colorado parents learned to recognize their child's mental illness, and what affect SBHCs had on their recognition process and initial decision to seek treatment, only one participant had access to a SBHC, so two of the five original research questions and subquestions had to be abandoned. As a result of examining the three remaining research questions through in-depth interviews with five mothers obtained through a purposeful criterion sampling, three essential themes emerged that comprised the essence of the phenomenon. A synopsis of the research questions, themes, aspects, and patterns is shown in Figure 6.

The findings of this study suggest that these Colorado mothers experienced the essence of the phenomenon of recognizing their child's mental illness as a process of "waiting to hear that 'normal' had stopped." Their lived experience involved a period of watchfulness, during which the mothers justified their increasing worry with the assumption that their child was progressing through a normal developmental phase or response, which would eventually pass. Due in part to the self-esteem they derived from being a good parent, their perception that this was a normal phase meant that they should be able to handle it, and so they continued waiting, and watching, and worrying. This waiting period did not end until someone else said or did something explicit to abruptly realign each mother's understanding, which enabled her to reframe the behaviors, and galvanized her to obtain treatment.

Research Questions	Themes, Aspects, Correlational Patterns
RQ1: How do parents describe their experiences of recognizing that their child's behaviors are related to a mental illness that requires treatment?	Theme 1 – Because it's your kid. Aspects: ♦ The self-esteem the mothers derived from being a parent ♦ Feelings of guilt about not recognizing sooner and/or having to let go as their child healed
Qual SubQ1: What impedes or enhances parents' perception and initial treatment decisions?	Theme 2 – It must be normal, so I should continue handling it. Aspects: ♦ Since the behaviors were attributed to a normal developmental phase or event, the mothers thought they should be able to handle it, despite their rising levels of distress and/or worry ♦ A period of deferring or putting off Correlational Patterns: Direct relationship between a prior close relationship with someone who had a mental illness, and both the ▪ Severity of their level of distress, and ▪ Length of time to recognition
Qual SubQ2: How and why do parents overcome barriers to problem recognition?	Theme 3 – In a Word … Validation Aspects: ♦ A sense of intuition ♦ The importance of hearing explicit words, typically those that connoted diagnosis or need for treatment

Figure 6. Alignment of research questions, themes, aspects, and patterns.

In the next chapter I relate the findings of this study to the research literature, to place what was learned from exploring this phenomenon within the context of the stream of knowledge. After describing the limitations of this study, I will discuss implications for policy makers and practitioners, along with recommendations for further research. Chapter 5 will conclude with possibilities for positive social change.

Chapter 5: Discussion and Recommendations

Introduction

To explore how Colorado parents learned to recognize their child’s behaviors as resulting from mental illness, I blended and triangulated qualitative and quantitative data gathered concurrently from a series of in-depth interviews with five mothers in the Pikes Peak Region of Colorado. This inquiry was undertaken to augment the evolving understanding of the intersection between public policy and treatment seeking for childhood mental illness in order to decelerate a growing public health crisis.

The research process revealed that the essence of the phenomenon of recognizing a child’s mental illness was—for these mothers—a process of *waiting to hear that “normal” had stopped*. In this chapter I will interpret the findings using the themes, aspects, and correlational patterns presented in Chapter 4. After examining the limitations of this study, I will offer recommendations for future action and research, and conclude with some implications for positive social change.

Interpretation of the Findings

The results of this study confirmed many of those in the literature on general and parental recognition of mental health issues. This research also augmented the knowledge base on prior experience with mental illness and its effects on parents’ recognition processes. Further, since this may be the first study to analyze the impact of various factors on the length of parents’ time to recognition of their child’s mental illness, the results contribute to a more thorough understanding of the recognition process while also generating new questions. I interpreted the findings of this study using its three research questions as a framework, although the themes, aspects, and correlations intertwine throughout the discussion.

Research Question 1

How do parents describe their experiences of recognizing that their child's behaviors are related to a mental illness that requires treatment?

Theme 1: Because it's your kid. The two aspects of this theme confirmed and augmented findings in the literature. One aspect comprised the feelings of guilt inherent in the parents' recognition process, which was tied to the other aspect, the self-esteem that all of the mothers appeared to derive from being a parent.

Guilt. The feelings of guilt described by the mothers in this study paralleled and extended the results of a similar study by Thomson et al. (2012) on parents in the United Kingdom with adolescents with anorexia. Thomson et al. (2012) found that the parents' feelings of guilt centered on their inability to recognize earlier and "make their child better themselves" (p. 49). While the aspect in this theme involved guilt at not recognizing earlier, it also marked a sense that somehow the parent might have caused or exacerbated the illness. Studies of parents in New Zealand (Crowe et al., 2011) and Australia (Richardson, Cobham, McDermott, & Murray, 2013) both noted the theme of self-blame due to perceived inadequacies in parenting, or dealing with their own disorder, which the comments by the Colorado mothers in this study echoed.

Parental self-efficacy. A finding in a study by Dempster, Wildman, Langkamp, and Duby (2012) indicated that parents who were not as confident in their abilities were more likely to seek help. The authors thus inferred that those parents who had higher levels of self-efficacy were both less likely to seek help, and less likely to be perceived by others as in need of help (Dempster et al., 2012). Pride and self-esteem in their abilities as a parent and a strong emotional commitment to their child were evident in the participants in my study (Crowe et al., 2011). However, it was unclear exactly how this sense of self-efficacy affected the recognition process, since my research presented evidence that high parental self-efficacy could be both an enhancement and a barrier to recognition.

In this study, two participants' descriptions regarding their sense of parental effectiveness were at opposite ends of the recognition spectrum, and one parent's experience spanned the spectrum. Amy ascribed her strong sense of parental competence in part to her watchfulness of her son's behaviors and her desire to avoid denial about the possibility of mental illness. In contrast, Susan believes that her high levels of confidence in her parenting actually obscured her recognition "because I didn't think that could happen to my kid. That we had done a good job raising her." Debra's experiences with her children encompassed both a low and a high level of self-efficacy. When recognizing her first son's mental illness, she described him as "the most challenging child I had ever faced," and in response she sought help through a plethora of parenting classes. However, it was due to his—and then her own—subsequent diagnoses that her confidence in her parenting escalated. The open communication she then instilled in her family was pivotal to her youngest son's disclosure that he needed help.

Self-efficacy appeared to be a strong component of treatment seeking for all of the mothers in this study. Once they recognized the need for mental health services for their child, they were prompt in obtaining them, and expressed guilt for not recognizing the need sooner. This seems counter to the findings in a study by Oldershaw et al. (2008), where once the parents were confronted with evidence that their child was engaging in self-harm, they wanted to “brush it under the carpet” and delay treatment, expecting that the behaviors would pass (p. 141). The importance of self-efficacy leads to a discussion of the second theme that emerged from this study. The interplay of parental self-efficacy with the perception that the behaviors were part of a normal developmental phase appeared to have a significant impact on the recognition process.

Research Subquestion 1

What impedes or enhances parents’ perception and initial treatment decisions?

Theme 2: It must be normal, so I should keep handling it. This finding showed the highest unanimity in responses among the five participants, with a strong grouping of four related barriers: (a) thought it was normal/child would outgrow it, (b) environmental explanation of behaviors, (c) didn’t think it was medical, and (d) didn’t think it was serious enough yet. These barriers contributed to participants’ delays in recognition.

As described by Oldershaw et al. (2008), this tendency towards a “wait and see approach” is a common theme in the literature (p. 141). The most recurring references involved confusion about what constituted mental illness, or misattribution of normal child/teen behaviors (Boydell et al., 2013; Epstein et al., 2010; Jorm, 2012; Logan & King, 2001; Moses, 2011; Prior et al., 2003; Sayal et al., 2010b; Sheppard, 2006; Thomson et al., 2012). The results of my study provided additional evidence about both blaming behaviors on external causes or stressors, and placing more emphasis on evidence that indicated the behaviors were normal (Farmer et al., 2012). Despite their varying levels of experience with mental illness, these mothers initially engaged in what Biddle, Donovan, Sharp, and Gunnell (2007) described as a "lay diagnosis" (p. 998), where they failed to include the behaviors into their frame of reference for mental illness (Prior et al., 2003). This indicates that the overriding barrier is one of categorization of symptoms versus an inability to recognize them (Biddle et al., 2007), and is consistent with sociological theories of illness behavior (Mechanic, 1995; Zola, 1975).

My assessment is that for the mothers in this study, this misclassification of behaviors as *normal* melded with their perceptions of self-efficacy and became an iterative and self-perpetuating cycle: Because they interpreted their child's behaviors as normal, this interpretation reinforced their perception that they, as effective parents, therefore could and *should* be able to wait until this phase passed and handle the behaviors without professional assistance. This assessment seems most congruent with the cycle of avoidance theoretical model developed by Biddle et al. (2007; Figure 1), in which the threshold for needing help constantly shifts as the person continually redefines their level of distress.

Where the results of my study diverged from the cycle of avoidance model is in the level of distress necessary to obtain help. Several authors described a level of extreme distress or even crisis in order to motivate help-seeking (Biddle et al., 2007; Brown, 2012; Murry et al., 2011; Wilson et al., 2012). Yet in my research, despite their accounts of varying and rising levels of distress, the majority (*n* – 4) of the Colorado mothers sought treatment for their child well before a crisis occurred. Based in part on triangulation with the patterns and correlations revealed by the statistical analyses, I concluded that these participants' prior experience with mental illness had a mitigating effect on the level of input necessary from their social network to motivate them to seek treatment. Instead of a crisis, they needed a word.

Patterns and correlations in barriers and facilitators. The triangulation of the one significant finding, the two non-significant yet important findings, and the qualitative data revealed a strong correlational pattern between the participants' prior experience with mental illness and a shorter period of recognition. Although I found two other studies in the literature that investigated the relationship of the length of delay to the reasons for delay (Christiana et al. 2000; Thompson et al., 2004), these studies considered individuals with mental illness, rather than parents. To my knowledge this is the first study that examined the relationship of various factors to the length of parents' time to recognition of their child's mental illness.

New questions emerged as I considered the factors that the participants did not rate highly as affecting their recognition. The mothers' lackluster endorsement of recognition help from teachers, pediatricians, and self-help resources was partially consistent with the literature. In this study, although 60% (n – 3) of the participants indicated that that teachers and self-help resources such as books and the internet had enhanced their recognition, in each case only one mother ranked these helps within their top three most important. And when contrasted with the 60% who selected a crisis or precipitating event as helping their recognition, the rankings for crisis were higher overall than the rankings for either teachers or self-help. Additionally, when triangulated with the interview transcripts, there was an indication that some of the participants may have been conflating support they received from teachers and school staff *after* their child's diagnosis with help prior to recognition.

Given the results from other studies that cited the importance of teachers and schools to parents' recognition (Arcia & Fernandez, 2003; Lindsey et al., 2012; Murry et al., 2011), I had expected the percentages and ranking in my study to be higher. In delving into this more deeply, I first noted that the populations for these three other studies were all from racial/ethnic minority demographics in the United States, specifically African-American and Latina parents, which is in contrast with my sample of predominantly Caucasian mothers. I then considered the results of the study by Bevaart et al. (2012), which examined the recognition of parents and teachers of Dutch children (ethnic majority and minority) separately, and the study of British teachers by Loades and Mastroyannopoulou (2010), which did not indicate the ethnicity of the students. Both studies indicated the teachers had better than an 87% rate of recognizing mental health problems (Bevaart et al., 2012; Loades & Mastroyannopoulou, 2010), and Bevaart et al. (2012) compared this to a 63.1% perception rate for the parents. A study of parents in Italy noted that teachers and parents differed in their abilities to recognize mental illness, and that teachers were responsible for more than twice as many referrals for treatment, although these were usually based on educational need (Pedrini et al., 2015). These results caused me to question—if teachers recognize mental illness earlier and more frequently than parents, why did not more of the mothers in my study cite teachers as a help to their own recognition? What is keeping these Colorado teachers and parents from communicating effectively on mental health issues?

For doctors, the results from this study were even lower. Only 40% (*n* – 2) of the participants selected a doctor as any help to their recognition, and one of these mothers indicated that the doctor who aided her recognition was a family friend, rather than her child's pediatrician. This low recognition by primary care physicians was very consistent with my findings in the literature (Ellingson et al., 2004; Horwitz et al., 2003; Sayal et al., 2010b; Thomson et al., 2012), and echoes the same question I had about teachers—what is impeding the effective communication on mental health issues between Colorado parents and their child's doctor? These two sets of parallel questions about teachers and doctors combined to increase my frustration at not being able to gather more data on the impact of school-based health centers (SBHCs) in this study, since they would appear to be an intersection between medical professionals, teachers, and parents. This knowledge gap is addressed in my recommendations for future research.

Research Subquestion 2:

How and why do parents overcome barriers to problem recognition?

Theme 3 – in a word … validation. Two interwoven aspects emerged in this research—the mothers' intuition that something wasn't quite right, combined with their apparent need to hear confirmation of this intuition from someone else in their social network. Social networks help define attitudes, beliefs, and expectations about normal development and behaviors, and researchers are observing that confirmation, encouragement, or intervention from the social network is frequently a component of recognition. In Gulliver, Griffiths, and Christensen's (2012) thematic analysis, they noted how common it was for someone else in adolescents' networks to recognize the problem first. In studies of parents, the need for legitimization of their concerns was evident (Arcia & Fernandez, 2003; Singer, 2009; Thomson et al., 2012). Other researchers framed the value of a social network as providing a standard with which to judge when behaviors crossed into the abnormal range (Moses, 2011), or helping them to categorize when something was truly *wrong* (Brown, 2012).

This need for confirmation was not limited to the literature on mental illness—there were parallels with parental recognition and help-seeking for other medical conditions. In a study by Ingram et al. (2013), parents exhibited similar patterns of uncertainty and the need for sanctioning from their social network or the internet before seeking professional care for their child's cough. An interesting difference was that when confronted with uncertainty about the implications of a cough, parents were more likely to default in favor of consulting a professional (Ingram et al., 2013), yet the results of my study indicated that the default response to uncertainty about behavioral issues was to assume it was due to normal or environmental causes, and to proceed with a form of *de facto* home care. This was consistent with findings in the literature, that people often do not consider emotional or behavioral issues as warranting professional health care (Erritty & Wydell, 2013; Sayal et al., 2010b).

I also found it interesting that none of the mothers in this study described any sort of reaching out beyond their immediate family in order to confirm or validate their concerns. The two participants who did describe seeking information did not do so in person, but instead used anonymous self-help sources such as magazines and the internet. This confirmed the part of the phenomenon that involved "*waiting* to hear that 'normal' had stopped," and seemed to require someone from their wider social network to take the initiative to bridge the communication gap. Thus the discussion comes full circle, with a final, unifying observation from the first theme.

Bringing the Themes Full Circle

As mentioned in Chapter 4, the title for the first theme—"because it's your kid"—was a version of a phrase used by three of the mothers in the interviews when asked for their advice. One of the reasons I asked the mothers to offer advice to others in similar situations was to discover things they felt had been lacking in their own recognition journey. The resounding refrain from all of the mothers was: *You are not alone—reach out, connect, and empower yourself to help your child*. This could imply that during their recognition experience, these mothers felt isolated, disconnected, and powerless, which sends a strong message to policy makers and practitioners: We need to reach out to parents, because they seem reluctant to start a conversation about their child's mental health outside of their family (Girio-Herrera, Sarno Owens, & Langberg, 2013). We should find supportive ways to begin the conversations, and create opportunities for the words to be said that can help re-frame parents' attributions of their children's behaviors. This call for wider solidarity underscores my discussion of recommendations for action and implications for social change, which is presented after considering the limitations of this study.

Limitations of the Study

Since a phenomenological methodology dominated my research design, the limitations include those generally associated with qualitative studies that rely on interview data. Specific limitations present in this study were due to the effects of a small sample size and the sampling method, the research instrument, and the potential for bias.

The small sample size and the criterion sampling strategy combined to constrain the transferability of the findings of this study. This was compounded by the relative homogeneity of the participants, in gender, age, geographic location, race, and socio-economic status. Therefore the results may not be representative of other Colorado parents, especially fathers and members of minority populations. The small number of participants also diminished the strength of the statistical tests, again limiting the generalizability of the results.

Using interview data as the cornerstone of the research protocol brought other limitations, such as possible distortion of responses due to participant bias, emotions, or lack of awareness (Patton, 2002). Since the participants were asked to recollect and reflect on their experiences, their narratives could have been impacted by recall error, a tendency to provide self-serving responses (Patton, 2002), or the inability to remember events or details. The request for poetry could also have contributed to recall error by an unintentional emphasis on certain aspects of their experience, possibly causing them to minimize or exclude other elements or recollections. Use of interviews could also have impacted the diversity of the participants, since potential respondents may have been deterred by the lack of anonymity, the amount of time required, or the gender and perceived Spanish-language proficiency of the researcher, all of which were evident on the advertisement flyer.

My personal biases and beliefs, and my skills as an interviewer, may also have limited the quality and quantity of data collected (Patton, 2002). I may have unintentionally exerted influence during the interviews—an effect known as reflexivity—through body language or facial expressions, through prior acquaintance and familiarity (Creswell, 2013), or from a perception of an asymmetric power differential by the participants (Kvale, 2006). Additionally, since I offered a financial incentive to participants, this may have affected the content and quality of their responses, especially if they felt a need to prove themselves worthy of the compensation.

Recommendations

This exploratory study was inspired by the public policy goals in the President's New Freedom Commission on Mental Health (PNFCMH, 2003), and I sought to gain insight into the problem of why mental health service delivery policies and programs are insufficiently responsive to the early help-seeking needs of parents and their children (Blau et al., 2010; Jensen et al., 2011; Keeton, Soleimanpour, & Brindis, 2012). Thus, the recommendations for action have been honed to be of most interest to public administrators and practitioners in the fields of health, education, and social work, and specifically the policymakers and residents of the state of Colorado. The recommendations for future research are broader, encompassing the arenas of public policy, social science, and methodology.

Recommendations for Action

The findings of this study indicate a need for continued network governance collaborations and systems of care (SOC) partnerships between health and education agencies at all levels of government, in order to (a) standardize and disseminate guidance, (b) enhance public understanding, and (c) facilitate dialogue on recognition of childhood mental health concerns. The foremost recommendation is for nationally recognized health organizations to collaborate on developing standard guidance on when behaviors deviate from normal development, and cross into an area of atypicality, disorder, or dysfunction. This guidance should be developed for the lay public (Ellingson et al., 2004). Partnerships should begin with agencies such as the Office of the Surgeon General, the American Academy of Pediatrics (AAP), the American Psychological Association (APA), and the National Institute of Mental Health (NIMH). An example of collaborative guidance that is already available is The 'Action Signs' Project toolkit (Jensen et al., 2011), produced for the Substance Abuse and Mental Health Services Administration (SAMHSA). Once consensus is reached on the guidance, governance networks should continue to collaborate on the dissemination of the guidance via public health campaigns.

Joining the results of this study with those of similar studies, it is likely that public health and information campaigns could be improved by targeting mothers, and appealing to their desire to be a *good* parent (Sayal et al., 2010b). This is not to imply that fathers should be neglected in the campaigns, since they are an important part of the only social network that mothers appear to reach out to—their immediate family. However, less data exists on fathers' perceptions, while there is substantial evidence that mothers typically are the ones who seek treatment for their children (Boulter & Rickwood, 2013). An important component of a public health campaign should be an emphasis on Mental Health Literacy (Jorm, 2012). The results of this study point to a correlation between experience with mental illness and a shorter time to recognition, which would seem to support the literature that demonstrates the efficacy of increasing public knowledge about prevention, recognition, care, and empowerment for mental and behavioral health needs (Centre for Health Program Evaluation, 2002; Jorm, 2012; Reavley & Jorm, 2011).

Another recommendation driven by the results of this study is for individuals, communities, and agencies to seek out ways to foster dialogue about behavioral health concerns. The PNFCMH (2003) established the goal of early screening for mental health concerns, and using universal screening methods by pediatricians and/or schools could be one way for policymakers to create opportunities for discussion and support. Government incentives could be implemented to facilitate and fund screening initiatives, and to supply the subsequent services that would be required for the children who sought treatment as a result of the screenings. Although the state of Colorado has set a leadership example by implementing a pilot program for universal mental health screening in schools (Schimke & Schimel, 2014), collaboration with prominent national health agencies could be beneficial in establishing common, research-based standards for universal screening (Kennedy, 2014).

A variety of financial incentives could be offered to promote early screening and help seeking. Governments at all levels can provide tax incentives, hospitals and health insurance agencies can offer rate reductions, and grants from governments and non-profit agencies can be used to motivate individuals and organizations to conduct screening and foster help-seeking.

At the local level, school districts and non-profits can partner to find more effective ways to appeal to and communicate with parents. In the literature, schools are often cited as sources of distress (Arcia & Fernandez, 2003; Murry et al., 2011; Sayal et al., 2006), perhaps due to the limited tools that administrators have to deal with mental health issues. Most responses are punitive—suspensions, expulsions, etc. The results of this study indicate that initiatives that promote familiarity with and understanding of symptoms might be effective. Programs such as mental health awareness months can be used as springboards to begin dialogue, and to send the message that *good* parents ask for help. Faith-based and community organizations can reiterate this message, and develop programs that encourage and reward help-seeking.

Recommendations for Further Research

To increase the value to public administrators and practitioners, this study should be continued throughout the state of Colorado, in order to include parents with access to SBHCs, and more diverse populations that are reflective of the state demographics. This would include but not be limited to rural areas, racial and ethnic minorities (especially Hispanic), different SES levels, and fathers/other caregivers. Based on the results of this research, studies that explore what is impeding conversations about childhood mental illness, especially between parents, teachers, and pediatricians, would provide valuable understanding for public officials on how to craft effective policies and programs to foster dialogue and support, to fulfill to Lisa's advice asking, "Who can we connect you with…?” To explore this from another angle, a meta-analysis of successful community programs that improve mental health literacy and facilitate conversations between families would be of benefit to policymakers at all levels.

In order to progress towards the goal of providing common standards for when behaviors diverge from normal development, research should be conducted on the efficacy and completeness of available tools such as The ‘Action Signs’ Project toolkit (Jensen et al., 2011). Studies that examine the effectiveness of universal assessments for health and education professionals would assist in their standardization and implementation. Specific emphasis should be placed on the effect of these tools on starting conversations with parents about their child’s mental health.

Larger and more widespread studies that incorporate quantitative methods would be of benefit, in order to increase generalizability and transferability of findings. Since self-efficacy emerged as a qualitative theme in this research, use of an instrument like the Parenting Sense of Competence (PSOC) scale (Johnston & Mash, 1989, as cited by Hankinson, 2009) could be used to quantify and correlate this variable with parents’ time to recognition.

Recommendations for methodology. In the course of this study, I made some small discoveries about different aspects of methodology that are worth sharing. I will offer comments on my experiences with the use of token monetary incentives, card sort tools, and poetic inquiry.

As presented in Chapter 4, in response to a comment by one of my validation panel members about a cultural norm to not attend appointments, I included a token monetary incentive of two dollars with the survey, to see if this would engender “a sense of reciprocal obligation” (Dillman, 2007, p. 153) to schedule and participate in the interview. The results in the literature described success for return rates on surveys (Boucher, Gray, Leong, Sharples, & Horwath, 2015; Dykema et al., 2012; Griffin et al., 2011), but I had not found any studies that examined this effect for interview attendance. The token incentive was mailed to six prospective participants who had qualified after completing the pre-screening questionnaire via telephone. Five of these women subsequently scheduled and attended interviews, while the one prospective participant who did not was from the target demographic, which I had most hoped to impact. Thus, my purely anecdotal evidence is that for this population, the token monetary incentive failed to have the desired result of motivating the prospective participant to attend the interview. My sense is that my use of a confirmation follow-up call a few days before the interview was the more effective motivator for interview attendance (P. Kuhl, personal communication, July 28, 2015), and this would be an area for future research.

Recommendations for card sorting. In Chapters 3 and 4, I described the use of a “card game” asking participants to rank cards with various factors based on the independent variables. When developing the research protocol, I made this decision in order to (a) facilitate gathering of quantitative data in an interview setting, (b) enrich those quantitative responses with immediate qualitative feedback, and (c) break up the potential monotony of an extended interview with a hands-on approach. Subsequent discussions with my Committee Methodologist revealed similarities between my technique and a method known as Q-methodology or Q-sort. Q-sort exhibits aspects of both quantitative and qualitative techniques, and adds value to research where subjective attitudes are sought (Simons, 2013). Participants order a selection of pre-determined statements into a Q-table ranging from ‘strongly disagree’ to ‘strongly agree’, which facilitates both a correlational analysis and an assessment of subjective meaning (Simons, 2013). By comparison, the technique used in my study was, to coin the phrase, more like a Q-ranking. This technique capitalized on the benefits of quantitative survey rankings, and mitigated some of the drawbacks inherent in this approach by augmenting it with qualitative tools. This allowed participants to describe details such as relative importance between ranked items (Ovadia, 2004), and rationale for prioritizing or excluding various items.

Other researchers are using variations on traditional Q-methodology (Dziopa & Ahern, 2011), and are reporting experiences similar to those in my study. Card-sorting techniques within an interview setting were found to be effective at exploring participants’ deliberations about the card subjects and their placement, including their understanding of the cards and their rationale for placement (Kampen & Tamás, 2014; Saunders & Thornhill, 2011), which echoed my experiences. Similar to my study, other researchers also noticed that participants seemed to enjoy the activity, and their active engagement in the task facilitated subsequent discussion during the interview (Drew, 2014; Saunders & Thornhill, 2011).

When continuing research into parental recognition, Q-techniques could prove valuable in quantifying parents’ subjective meanings on mental health terms such as *anxiety* and *depression*, and this technique could be effective in both English and

Spanish. Use of *Q-rankings* could benefit policymakers in developing guidance to help parents differentiate symptoms from normal developmental phases through greater understanding of the relative importance that parents place on the severity of symptoms, their reasons for delaying, and their rationale for finally distinguishing when a *normal* behavior crosses the line to require help-seeking.

More research on the efficacy, validity, and reliability of the *Q-ranking* technique may prove beneficial to researchers conducting mixed-methods studies. Rather than using separate quantitative and qualitative tools in tandem, the *Q-ranking* “card game” in my study blended quantitative and qualitative aspects into a single tool. As such, it combined the strengths and weaknesses of both a ranking question on a survey and an interview, but to what extent? This is where further research on the efficacy of this technique would be enlightening—to determine the validity and reliability of this as a tool for mixed-methods inquiry. Tradeoffs in feasibility, richness of data, and generalizability should also be examined, and contrasted with other data-gathering and evaluation tools (Danielson, Tuler, Santos, Webler, & Chess, 2012), especially for use in mixed-method studies.

Recommendations for poetic inquiry. Robert Frost (2007) said of poetry, “It begins in delight and ends in wisdom” (p. 132). My initial decision to incorporate elements of poetic inquiry into this research evolved from an assignment in a Walden University course on Advanced Qualitative Reasoning and Analysis, which challenged students to move beyond the five approaches to qualitative research presented by Creswell (2013). Poetry offered a natural fit with the qualitative strand in this study, and I became curious about how effective the use of poetic inquiry might prove in public policy research, especially when it came time to communicate the findings to policymakers, administrators, and the public (Hordyk, Soltane, & Hanley, 2014). The literature showed there was growing interest in use of poetic and art-based research in many disciplines, including business and management (Nocker & Junaid, 2011), nursing (Kidd, Zauszniewski, & Morris, 2011), education (Bishop & Willis, 2014; Christianakis, 2011; Hickey, 2012), and social work (Sjollema, Hordyk, Walsh, Hanley, & Ives, 2012; Hordyk et al., 2014), so I incorporated poetic techniques into my research.

As a tool for data analysis, my experiences confirmed those found in the literature, most notably by providing additional tools to enhance a variety of perspectives, stimulate new ideas, and enhance communication of complex concepts (Janesick, 2011; McCulliss, 2013; Prendergast, 2009). Adhering to a poetic structure helped me condense and distill words and meanings, similar to the results of a study by Furman and Dill (2015). Where the results of this study extend the literature on poetic inquiry is in the use of poetry as a component of data collection. This is one of a very few studies I have found outside of academic settings that specifically requests participants to be involved in the creation of personal poems as a part of the data collection. I found that the reflective process that the participants engaged in when finding or composing their poems enabled them to synthesize and the express essential parts of their experience, which provided me with an enhanced understanding, and additional material for triangulation. Also, the majority of the mothers (*n* – 4) shared that they enjoyed the process of writing or selecting a poem, and that they found the experience a bit cathartic. An arts-based research study by Walsh, Rutherford, and Crough (2013) reported similar findings when they asked participants to create data products such as photographs, stories, poems, films, and drawings about their experiences, and described the process as a catalyst for "personal and social change" (p. 135).

As I prepare myself for the role of scholar-leader, with the responsibility and privilege of sharing the results of my study with diverse audiences in government, non-profit, and community settings, I predict that poetic inquiry will offer unique ways to influence people at a fundamental level (Barker, 1997). When I communicate these findings to various public agencies, poetry is more likely to engage the audiences than an academic report (Hordyk et al., 2014), and provide greater richness. Poetry, metaphor, and story can evoke an emotional connection and communicate empathy for a particular viewpoint (Simmons, 2006), and can also be used as a method for changing opinions, which is an essential component of leadership (Clawson, 2012).

These small successes in my study, combined with the growing use of arts-based research in literature variety of disciplines, embolden me to recommend further public policy research efforts that incorporate elements of poetic inquiry, specifically creation of participant poems as data for the study, and as a means of sharing research results to encourage action. These studies should shift the current focus away from researchers as the creators of poems, and inquire into other ways in which poetry might serve to enhance research effectiveness, and also increase participant empowerment for social change.

Implications for Positive Social Change

When My Brother Was an Aztec

he lived in our basement and sacrificed my parents
every morning. It was awful. Unforgivable. But they kept coming
back for more. They love him, was all they could say.

[stanzas and line omitted]

...My brother shattered and quartered them before his basement festivals—
waved their shaking hearts in his fists,

while flea-ridden dogs ran up and down the steps, licking their asses,
turning tricks. Neighbors were amazed my parents' hearts kept
growing back—It said a lot about my parents, or parents' hearts.

(Excerpts from a poem on mental illness by Natalie Diaz [Diaz, 2012])

An estimated 15 million children in the United States suffer from a diagnosable mental illness (American Psychological Association, 2014)—multiply this by the number of family members who suffer alongside, and the magnitude of this emerging public health crisis begins to become clear. Parents—conscientious, caring, "good" parents—are struggling to recognize the difference between normal developmental behaviors and those related to treatable medical conditions.

Seeds of positive social change were sown during the interviews, when the participants experienced the empowerment that came from sharing their stories and their poetry. As I disseminate the knowledge gained from this research with scholars and public officials, I hope to bring greater awareness about the need for standardized public policy guidance on how early signs of disorders can be differentiated from *normal* developmental behaviors. Emphasis should be placed on funding proven programs that increase understanding and recognition of mental health issues—programs such as Mental Health Literacy and Mental Health First Aid.

The results of this study can also inform current debates on early and universal mental health screenings in both primary care and educational settings. These types of tools create ways for professionals in the social network, specifically doctors, nurses, and teachers, to initiate conversations with parents. Examples include questionnaires used at primary care appointments or by school nurses, which identify areas worthy of further exploration and conversation.

By extension, improving childhood diagnosis and care could have a long-term impact on reducing rates of homelessness, prison overpopulation, school dropout rates, and child abuse and neglect. Investing in programs and policies that promote parents' early recognition may enhance the quality of life for millions of children and their families.

Conclusion

As policymakers, practitioners, scholars, and neighbors, we can do more to respond to the early help-seeking needs of families. This study explained parental recognition as a process of "waiting to hear that 'normal' had stopped," and confirmed previous findings that parents tend to mis-categorize symptoms of their child's mental illness as normal behaviors in a passing developmental phase. Additionally, this study revealed that prior experience with mental illness appears to decrease the time necessary for parents to recognize their child's mental health issues.

Network governance collaborations, as a foundation for and natural extension of public policy, and public health campaigns can be used to standardize and disseminate guidance, enhance public understanding, and facilitate conversations about recognition of childhood mental health concerns. By considering the results of this study alongside the growing evidence in the literature, we are learning that engaging parents in meaningful dialogue about childhood mental health issues—and helping them differentiate between typical stages of development—is likely to facilitate recognition and treatment-seeking. It will also ensure we heed the poignant message from Susan: "And that's, that's always the biggest thing, because it's frustrating to know… that there are other people out there, but no one talks about it."

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Appendix A: The Cycle of Avoidance Model Permissions

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Appendix B: Parent-Mediated Pathway to Mental Health Services for Adolescents Model Permissions

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Appendix C: Screening Questionnaire Guide

Screening Questionnaire

Name: ___________________________________ Date: _______________

Note: If the answer to any of the **numbered questions** *is "no," the inquirer does not meet the eligibility requirements. Inform them, thank them for their time, and ask if they would let others who might qualify know about this opportunity.*

- [Ice breaker] Thank you for inquiring about this research study. I'm curious to know how you found out about it?

- If you don't mind, I have a few questions for you, to make sure you are eligible to participate. Is that alright?

1. **Do you have a child who has received a diagnosis of a psychological disorder? Y / N**

2. **Did your child receive this diagnosis within the past year? Y / N**

- How old is your child? ________

3. **Are you the person who is responsible for making the medical treatment decisions for the child we've been referring to? Y / N**

4. **Do you live in a neighborhood with access to a School-based Health Center** (SBHC?) **Y / N**

- Does your child use the services at a SBHC? Y / N

- One aspect of the study includes the use of poetry. Would you be willing to consider composing a poem, or finding a poem or a song that's already been written, that describes your experiences or feelings? Y / N

~*~*~*~*~*~*~*~*~*~*~*~*~*~*~**~*~*~*~*~*

You meet the eligibility requirements for this study. ☺

Before I ask for your contact information and we schedule an interview, do you have any questions for me?

[*After questions are answered*] … Let me tell you about the details then. If you have questions at any time, please let me know.

The purpose of this study is to understand the process that parents [caregivers] go through when recognizing that their child has a mental illness. I also hope to learn if the presence of a SBHC has any effect on the recognition process.

page 1 of 2

The study will take place in two parts. The first part will take place at your convenience, but should be completed prior to the second half, which is an interview. Before the interview, I will send you a short questionnaire that will ask for basic information, and then it will ask you to reflect on your experiences of recognition. Part of this reflection will include writing or finding a poem or song that reflects your experiences or feelings during or about the recognition process. While this may seem unusual, this portion of the research process will be very valuable to the study. Although you may take as much time as you like, I don't expect you to devote more than an hour, unless you want to. Other participants reported that they spent between XX and XX minutes on this part of the study.

Do you have any questions or concerns before we continue?

The second part of the study involves an interview, and may take up to an hour and a half, although the average length is about one hour. We'll schedule the interview at a time and location that is convenient for you, and I will be asking for your permission to record the conversation. During that time I want to hear your experiences of how you learned to recognize your child's disorder. After that, I'll also ask several specific questions about your experiences.

Any questions? Would you like to participate in this study? Y / N

Let me get your contact information, and then we'll set a date for the interview.

- Confirm their name.
- Would you prefer to receive the questionnaire by email, fax, or regular mail?
    - E-mail address ______________________________
    - Fax #
    - Mailing Address

- What is the best telephone number for me to reach you?

- What is another number, as a backup?

- Try to select a date, time, and location for the interview, in about a week or two

  Date ______________________________

  Time ____________________

  Location ____

Appendix D: Advertisement

* * * * * * * * * * * * *

Does your child have behavior problems because of a disorder?

* * * * * * * * * * * * *

Be a part of a research study
for parents of children with a disorder

For your participation you will receive $15

You may be eligible to participate if:

- **Your child received a diagnosis of a psychological disorder within the past 12 months**
- **You live in a neighborhood with access to a School-based Health Center**

Study consists of a survey and an interview. To volunteer, or for more information, call or e-mail Lori Salgado at:

719-510-3037
lori.salgado@waldenu.edu

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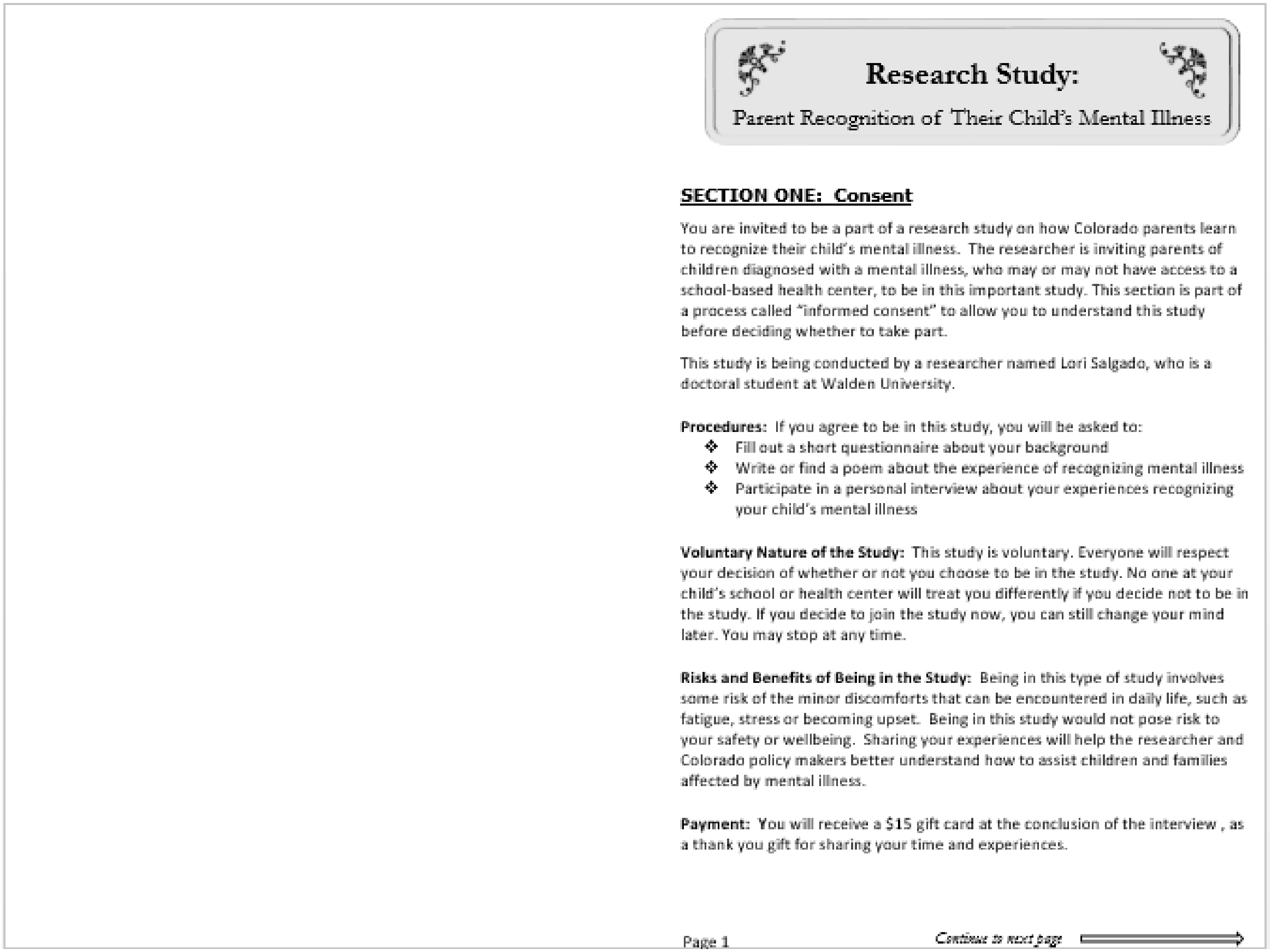
Appendix E: Pre-Interview Questionnaire



Research Study:

Parent Recognition of Their Child's Mental Illness

SECTION ONE: Consent

You are invited to be a part of a research study on how Colorado parents learn to recognize their child's mental illness. The researcher is inviting parents of children diagnosed with a mental illness, who may or may not have access to a school-based health center, to be in this important study. This section is part of a process called "informed consent" to allow you to understand this study before deciding whether to take part.

This study is being conducted by a researcher named Lori Salgado, who is a doctoral student at Walden University.

Procedures: If you agree to be in this study, you will be asked to:

- Fill out a short questionnaire about your background
- Write or find a poem about the experience of recognizing mental illness
- Participate in a personal interview about your experiences recognizing your child's mental illness

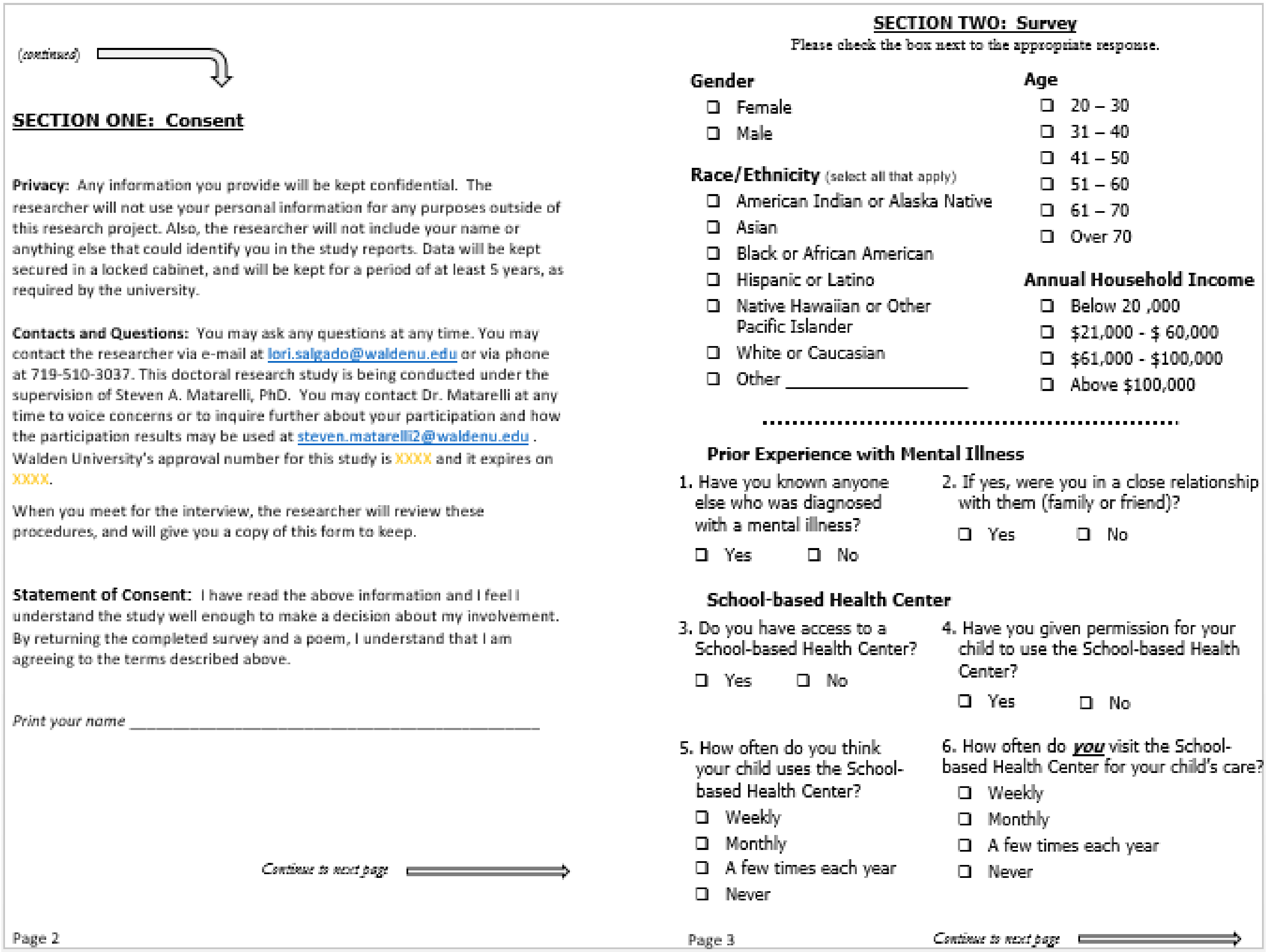
Voluntary Nature of the Study: This study is voluntary. Everyone will respect your decision of whether or not you choose to be in the study. No one at your child's school or health center will treat you differently if you decide not to be in the study. If you decide to join the study now, you can still change your mind later. You may stop at any time.

Risks and Benefits of Being in the Study: Being in this type of study involves some risk of the minor discomforts that can be encountered in daily life, such as fatigue, stress or becoming upset. Being in this study would not pose risk to your safety or wellbeing. Sharing your experiences will help the researcher and Colorado policy makers better understand how to assist children and families affected by mental illness.

Payment: You will receive a $15 gift card at the conclusion of the interview , as a thank you gift for sharing your time and experiences.

Page 1

Continue to next page ⟹



(continued)

SECTION ONE: Consent

Privacy: Any information you provide will be kept confidential. The researcher will not use your personal information for any purposes outside of this research project. Also, the researcher will not include your name or anything else that could identify you in the study reports. Data will be kept secured in a locked cabinet, and will be kept for a period of at least 5 years, as required by the university.

Contacts and Questions: You may ask any questions at any time. You may contact the researcher via e-mail at lori.salgado@waldenu.edu or via phone at 719-510-3037. This doctoral research study is being conducted under the supervision of Steven A. Matarelli, PhD. You may contact Dr. Matarelli at any time to voice concerns or to inquire further about your participation and how the participation results may be used at steven.matarelli2@waldenu.edu . Walden University's approval number for this study is XXXX and it expires on XXXX.

When you meet for the interview, the researcher will review these procedures, and will give you a copy of this form to keep.

Statement of Consent: I have read the above information and I feel I understand the study well enough to make a decision about my involvement. By returning the completed survey and a poem, I understand that I am agreeing to the terms described above.

Print your name ____

Continue to next page ⟹

Page 2

SECTION TWO: Survey

Please check the box next to the appropriate response.

Gender

- ☐ Female
- ☐ Male

Race/Ethnicity (select all that apply)

- ☐ American Indian or Alaska Native
- ☐ Asian
- ☐ Black or African American
- ☐ Hispanic or Latino
- ☐ Native Hawaiian or Other Pacific Islander
- ☐ White or Caucasian
- ☐ Other ________________

Age

- ☐ 20 – 30
- ☐ 31 – 40
- ☐ 41 – 50
- ☐ 51 – 60
- ☐ 61 – 70
- ☐ Over 70

Annual Household Income

- ☐ Below 20 ,000
- ☐ $21,000 - $ 60,000
- ☐ $61,000 - $100,000
- ☐ Above $100,000

……………………………………………………

Prior Experience with Mental Illness

1. Have you known anyone else who was diagnosed with a mental illness?

☐ Yes ☐ No

2. If yes, were you in a close relationship with them (family or friend)?

☐ Yes ☐ No

School-based Health Center

3. Do you have access to a School-based Health Center?

☐ Yes ☐ No

4. Have you given permission for your child to use the School-based Health Center?

☐ Yes ☐ No

5. How often do you think your child uses the School-based Health Center?

- ☐ Weekly
- ☐ Monthly
- ☐ A few times each year
- ☐ Never

6. How often do ***you*** visit the School-based Health Center for your child's care?

- ☐ Weekly
- ☐ Monthly
- ☐ A few times each year
- ☐ Never

Page 3

Continue to next page ⟹

SECTION THREE:

Provide a Poem about Recognizing Mental Illness

Poetry is a form of writing that touches our emotions and conveys the essence of an experience. Although writing a poem about recognizing mental illness may seem unusual or intimidating to some, use of a poetic format could help reveal important insights that will benefit this study.

The poem does not need to be lengthy or complex, but it should be ***meaningful*** to you.

You may find a poem or song, online or in a book, or you may choose to compose one.

* * *

If you decide to write a poem but aren't sure how to begin, here are a couple of easy formats:

1. **Haiku** – a 3-line, 17-syllable poem. Traditionally, the first and last lines will each have five syllables, and the middle line will have seven syllables. So, the pattern of syllables would be:

Line 1: 5 syllables
Line 2: 7 syllables
Line 3: 5 syllables

Another way to visualize the syllable pattern is:

1 2 3 4 5
1 2 3 4 5 6 7
1 2 3 4 5

Here is an example of a haiku poem by Murakami Kijo:

First autumn morning
the mirror I stare into
shows my father's face.

Continue to next page ⟹

2. **Diamante** – a 16-word, 7-line poem format that forms the shape of a diamond. This format uses nouns, adjectives, and verbs about a topic, and arranges them in a specific pattern:

Noun
Adjective, Adjective
Verb, Verb, Verb
Noun, Noun, // Noun, Noun
Verb, Verb, Verb
Adjective, Adjective
Noun

Some people adapt this format to explore two sides of a topic, so that the poem transitions in the middle to a description of the opposite side. Here are examples of each type of diamante poem, by Dr. Ram Mehta:

Mother
caring, kind
nursing, assisting, guiding
teacher, adviser, counselor, caregiver
leading, molding, supervising
tender, understanding
friend

Father
strong, industrious
building, directing, sacrificing
family head, director, leader, manager
hardworking, supporting, teaching
courageous, patient
Mother

Remember, these formats are offered only as ideas and inspiration—please don't let them limit you. **You may use any format.**

Enjoy this opportunity for expression on this important topic. If you have any questions or concerns with this phase of the study, please do not hesitate to contact the study director, Lori Salgado, at 719-510-3037, or lori.salgado@waldenu.edu .

Continue to next page ⟹

Thank You !

For sharing your thoughts and
supporting this research.

Please ***bring your poem***
and the completed questionnaire with you
to the interview on

______________________.

Appendix F: Interview Guide

Date: ________________________ ID # __________

Introduction:

Thank you for your help in this study. My name is Lori Salgado and before we begin the interview I would like to talk to you about your participation in this research study. Its purpose is to understand how parents recognize their child's mental illness, and what effect a school-based health center may have on that process. I hope to understand this experience from your point of view—to know what you know, in the way you know it.

I want to make sure you understand that participation in this study is voluntary, and you that may stop the interview at any time.

The interview should take about an hour, and we will be reviewing a lot of information, all of which is important for this research project. Since I don't want to miss any of your comments, would it be alright if our conversation was taped? I will also be taking some notes during the session, but I can't possibly write fast enough to get it all down.

During this interview, you may feel tired, stressed, or emotional, but beyond that there should be no other risks to your safety or wellbeing. All of your responses will be kept confidential. This means that your interview responses will only be shared with research team members and we will ensure that any information we include in our report does not identify you. Remember, you don't have to talk about anything you don't want to and you may ask questions or end the interview at any time.

After we have finished the interview, as a token of gratitude for sharing your time and experiences, I will offer you a choice of a $15 gift card to either a local supermarket or to WalMart.

Are there any questions about what I have just explained?

Are you willing to participate in this interview? [Signature]

🔓 = Indicates a potential probe

Interview Guide	Notes / Counters
Icebreaker 1. First, tell me a little about yourself—where you grew up, some of your hobbies and interests, and so forth. 2. Now tell me about your child—the one we'll be referring to most in this interview. What are they like? What are their hobbies and interests?	

Awareness
3. I understand that your child has received a diagnosis of a mental disorder--is that correct? Please share with me your story of how you learned to recognize that your child had this disorder. I want to learn not only what happened, but how it all happened and how you felt about it.
🔓 Why does that stand out in your memory?
🔓 Why do you think you noticed that?
🔓 How did that make you feel?
3a. When did you first question that your child's behavior might not be typical? [*ask this only if a date or time reference does not emerge in the narrative*]
	age _______ grade _______ year _______
	Reason(s)
	Behaviors
	Child Characterizations/Attributions
	Attribution to recognition
	___ *Parent's self-realization*
	___ *someone else pointed it out*
	    ___ *family member* _________________
	    ___ *friend*
	    ___ *teacher*
	    ___ *SBHC staff*
	    ___ *pediatrician*
	    ___ *other* __________________________
	      role _____________________________
	Reference to SBHC
	___ *none*
	___ *some*
	___ *specific mention of help*
	___ *specific mention of barrier*
	Reference to school
	___ *none*
	___ *some*
	___ *specific mention of help*
	___ *specific mention of barrier*
	Crisis or Precipitating event

Treatment Decision & Recognition 4. Describe the point when you truly believed your child had a psychological disorder that required professional treatment. 🔓 What was it like prior to that understanding? 🔓 What led you to that understanding? 🔓 How did other people respond to that? 🔓 What were other people doing then? 4a. When did this take place? [*ask this only if a date or time reference does not emerge in the narrative*]	
Recognition – Facilitators 5. What were some of the things that helped you recognize that ____'s behaviors were related to a mental illness? 🔓 Why do you think that helped you?	***self*** ***prompt*** ___ ___ *1. Social network = Family, friend, religious, teacher, school staff, SBHC, pediatrician, law enforcement, other* __________________________ ___ ___ *2. Prior experience with mental illness*

🔓 How did you feel about that? 🔓 Why do you think you noticed that? 5a. To make sure I have this correct—you mentioned that these things helped you recognize that your child's behaviors were related to a disorder [*List the items they recounted on individual cards, and display the cards*]—is this right? These are some things that other parents have mentioned helped them [*Display the cards*]. Would you please rank order these starting with those things that helped you the most [at the top], to those that were the least help on your ability to recognize [bottom]. 5b. Tell me why you put them in this order.	___ ___ *3. Media = TV, radio, PSA, etc.* ___ ___ *4. Self-help = books, magazines Internet, etc.* ___ ___ *5. Crisis /Precipitating event* ___ ___ *6. Other ____________________* ___ ___ *7. Other ____________________* ***Rank*** *Social Network* ___ *Family* ___ *Friend* ___ *Teacher* ___ *School Staff* ___________________________ ___ *SBHC* _______________________________ ___ *Pediatrician* ___ *Religious* _____________________________ ___ *Law enforcement* ___ *Other Soc. Net.* _________________________ ___ *Other Soc. Net.* _________________________ ___ *Prior experience with mental illness* ___ *Media = TV, radio, PSA, etc.* ___ *Self-help = books, magazines Internet, etc.* ___ *Crisis /Precipitating event* ___ *Other* ________________________ ___ *Other* ________________________
Recognition – Inhibitors 6. Tell me about some of the things that got in the way, or prevented, your recognizing the behaviors as related to a mental illness? 🔓 Why do you think that got in the way? 🔓 How did you feel about that? 🔓 Why does that stand out in your memory? 6a. To clarify, these are the things you	***self prompt*** ___ ___ *1. Thought it was normal/ child would outgrow it* ___ ___ *2. Didn't think it was serious enough yet* ___ ___ *3. Didn't think it was medical/ mental illness (personality, etc.)* ___ ___ *4. Environmental explanation of behaviors (parenting, peers, stress, event, etc.)* ___ ___ *5. Religious explanation of behaviors* ___ ___ *6. Thought I could handle it myself* ___ ___ *7. Worried about what people would say / Stigma / Blame* ___ ___ *8. Didn't know where to go/ who to turn to* ___ ___ *9. Husband/ Family didn't think it was necessary* ___ ___ *10. Cost or Accessibility of services* ___ ___ *11. Lack of insurance*

mentioned that got in the way, or prevented, your recognizing your child's behaviors as related to a mental illness. [List the items they recounted on individual cards, and display the cards] These are some barriers that other parents have mentioned. [Display the cards]. Please rank order these from strongest barrier to least impact on your ability to recognize. 6b. Tell me why you put them in this order.	___ ___ *12. Didn't like or believe in doctors* ___ ___ *13. Didn't want medication* ___ ___ *14. No previous experience with mental illness* ___ ___ *15. Other ____________________* ***Rank*** ___ *Thought it was normal/ child would outgrow it* ___ *Didn't think it was serious enough yet* ___ *Didn't think it was medical/ mental illness (personality, etc.)* ___ *Environmental explanation of behaviors (parenting, peers, stress, event, etc.)* ___ *Religious explanation of behaviors* ___ *Thought I could handle it myself* ___ *Worried about what people would say / Stigma / Blame* ___ *Didn't know where to go/ who to turn to* ___ *Husband/ Family didn't think it was necessary* ___ *Cost or Accessibility of services* ___ *Lack of insurance* ___ *Didn't like or believe in doctors* ___ *Didn't want medication* ___ *No previous experience with mental illness* ___ *Other ____________________*
Recognition – Facilitators (Referring to responses from Question 6) 7. What helped you overcome that [particular barrier of] ____? 🔓 Why do you think that helped you? 🔓 If ____ hadn't been there, what do you think would have happened? 7a. How important (1-7) was ____ in helping you overcome that barrier? [Repeat for each facilitator variable cited]	***self prompt*** ___ ___ *1. Social network = Family, friend, religious, teacher, school staff, SBHC, pediatrician, law enforcement, other _________________________* ___ ___ *2. Prior experience with mental illness* ___ ___ *3. Media = TV, radio, PSA, etc.* ___ ___ *4. Self-help = books, magazines Internet, etc.* ___ ___ *5. Crisis /Precipitating event* ___ ___ *6. Other ____________________* ___ ___ *7. Other ____________________* *Not Moderately* *Extremely* *Important Important* *Important* *1 – 2 – 3 – 4 – 5 – 6 – 7*
SBHC Now I want to shift a bit and explore what effect the school-based health center may or may not	*SBHC* ___ *none available* ___ *wasn't aware of a SBHC* ___ *aware but didn't use*

have had on your recognition experience.	___ *specific mention of barrier* ___ *specific mention of help* ___ *Other* ____________________________
8. First, tell me a little about the SBHC in your community.	
8a. How important (1-7) was the presence of a SBHC in your awareness that your child's behaviors were not typical?	*Not Moderately* *Extremely* *Important Important* *Important* *1 – 2 – 3 – 4 – 5 – 6 – 7*
8b. How important (1-7) was the presence of a SBHC in your ability to recognize your child's disorder?	
8c. How important (1-7) was the presence of a SBHC in your decision to seek treatment for your child?	*Not Moderately* *Extremely* *Important Important* *Important* *1 – 2 – 3 – 4 – 5 – 6 – 7*
9. If there had not been a SBHC, what effect would that have had on your recognition experience? 🔓 Tell me more about that. 🔓 Can you give me an example? 🔓 Why does that matter? 🔓 If I told you that another SBHC had a policy that required / prohibited ____ [that issue], how would you feel about a policy like that?	*Not Moderately* *Extremely* *Important Important* *Important* *1 – 2 – 3 – 4 – 5 – 6 – 7* *Hypothetical Lack of SBHC* ___ *no affect* ___ *significant crisis* ___ *extended time to recognition / treatment* ___ *Other* ____________________________
Poetry 10. Did you bring the poem that you wrote or found? Would you read it to me, or may I read it now? 10a. Thank you for taking the time to do this. Is there anything you want to share about this poem, or about your experiences writing / finding it? 🔓 Request any necessary clarifications 🔓 Probe any themes	

Concluding We're almost finished with the interview part of the survey, and I only have 2 more questions before we take a break. 11. Suppose I was a parent who was very concerned about my own child's behaviors, and I came to you—what advice would you offer me? 12. Now that we're at the end of the interview, are there any questions that I did not ask that you think I should have? 🔓 What are they? 🔓 Any others? [Repeat as necessary] ☺	

Conclusion:
This concludes the interview—thank you for sharing your experiences! Do you have any questions for me?

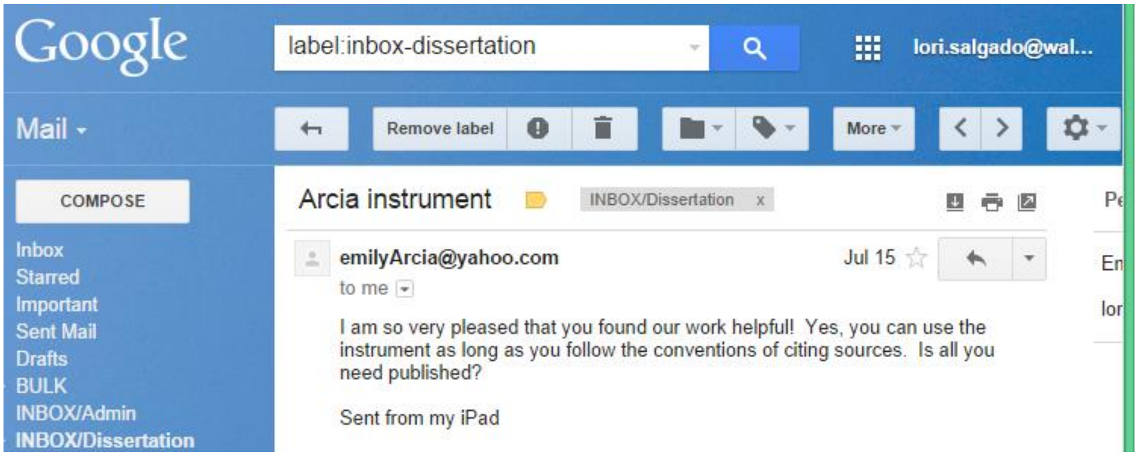
As I review the tapes and my notes, I may need to clarify some things. May I contact you with questions? [*confirm contact data … phone, e-mail, address*]

I appreciate you writing / bringing your poem—this will provide valuable insights. If you decide to write or find another poem, I would be very interested in receiving it.

> [If they did not bring the poem] Although you weren't able to bring a poem today, if you decide to write or find one, I would be very interested in receiving it. May I follow up with you in a week or so about this?

Thank you again for your time [*offer compensation*].

Appendix G: Permission to Use Arcia Instrument



Arcia instrument

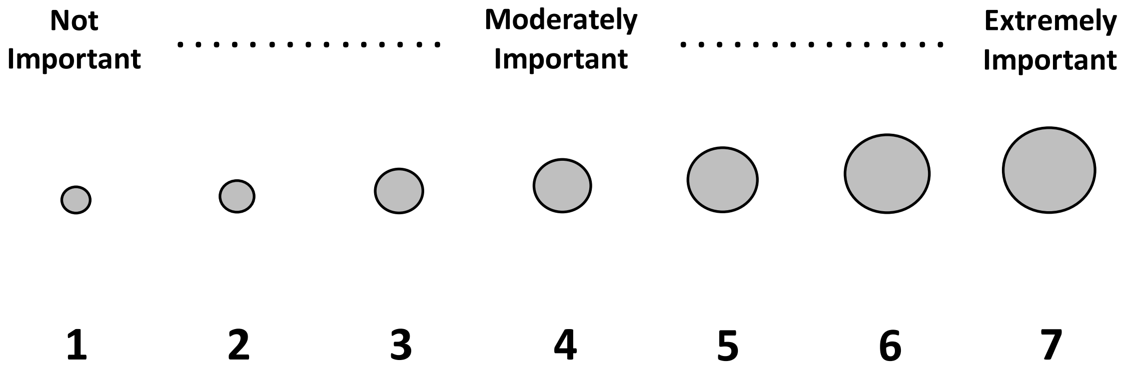
emilyArcia@yahoo.com Jul 15

to me

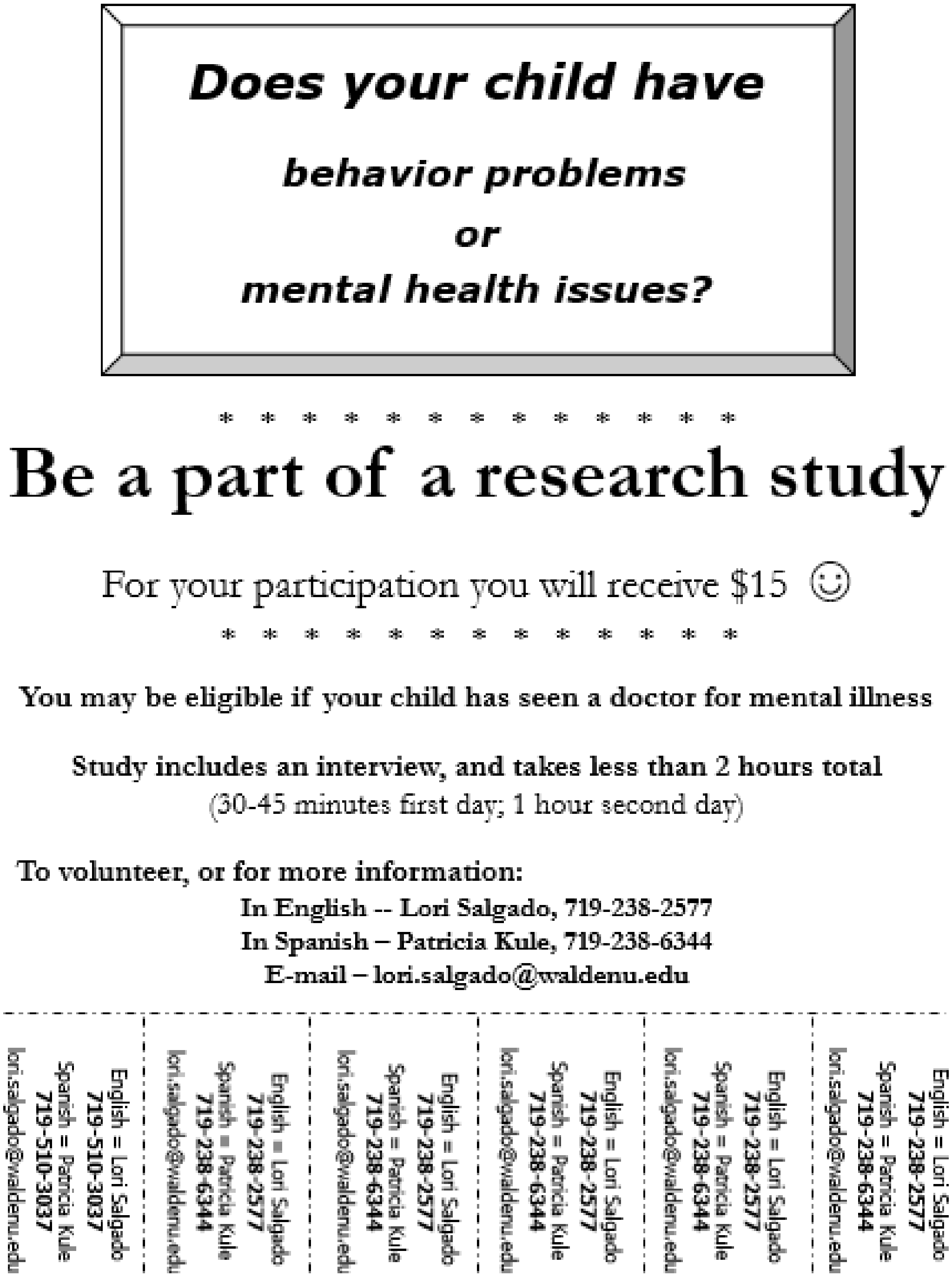
I am so very pleased that you found our work helpful! Yes, you can use the instrument as long as you follow the conventions of citing sources. Is all you need published?

Sent from my iPad

Appendix H: Rating Card With Scale



Appendix I: Final Advertisement (English)



Does your child have

behavior problems

or

mental health issues?

* * * * * * * * * * * * *

Be a part of a research study

For your participation you will receive $15 ☺

* * * * * * * * * * * * *

You may be eligible if your child has seen a doctor for mental illness

Study includes an interview, and takes less than 2 hours total
(30-45 minutes first day; 1 hour second day)

To volunteer, or for more information:
In English -- Lori Salgado, 719-238-2577
In Spanish – Patricia Kule, 719-238-6344
E-mail – lori.salgado@waldenu.edu

English = Lori Salgado
719-510-3037
Spanish = Patricia Kule
719-510-3037
lori.salgado@waldenu.edu

English = Lori Salgado
719-238-2577
Spanish = Patricia Kule
719-238-6344
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lori.salgado@waldenu.edu

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719-238-2577
Spanish = Patricia Kule
719-238-6344
lori.salgado@waldenu.edu

Appendix J: Updated Screening Questionnaire Guide

Screening Questionnaire

Name: ____________________________________ Date: ________________

Note: If the answer to any of the **numbered questions** *is "no," the inquirer does not meet the eligibility requirements. Inform them, thank them for their time, and ask if they would let others who might qualify know about this opportunity.*

- [Ice breaker] Thank you for inquiring about this research study. I'm curious to know how you found out about it?

- If you don't mind, I have a few questions for you, to make sure you are eligible to participate. Is that alright?

1 Do you care for a child who has a mental illness?
Y / N

- Did a doctor tell you about this illness? Y / N

2. Did the doctor tell you about this illness within the past year? Y / N

- How old is your child? ________

3. Are you the person who is responsible for making the medical treatment decisions for the child we've been referring to? Y / N

4. Does your child attend a school with a School-based Health Center (SBHC?) **Y / N**

- One aspect of the study includes the use of poetry. Would you be willing to consider composing a poem, or finding a poem or a song that's already been written, that describes your experiences or feelings about your child's mental illness? Y / N

~*~*~*~*~*~*~*~*~*~*~*~*~*~*~**~*~*~*~*~*

You meet the eligibility requirements for this study. ☺

Before I ask for your contact information and we schedule an interview, do you have any questions for me?

[*After questions are answered*] … Let me tell you about the details then. If you have questions at any time, please let me know.

The purpose of this study is to understand the process that parents [caregivers] go through when recognizing that their child has a mental illness. I also hope to learn if the presence of a SBHC has any effect on the recognition process.

page 1 of 2

The study will take place in two parts—a survey, and then an interview. The survey will be mailed to you, and can be completed at your convenience. It will ask you to reflect on your experiences of recognizing your child's mental illness. Part of this reflection will include writing or finding a poem or song that reflects your experiences or feelings during or about the recognition process. While this may seem unusual, this portion of the research process will be very valuable to the study. Although you may take as much time as you like, I don't expect you to devote more than 30-45 minutes, unless you want to. Other participants reported that they spent between 30 and 90 minutes on this part of the study.

Do you have any questions or concerns before we continue?

The second part of the study involves an interview, and may take up to an hour and a half, although the average length is about one hour. We'll schedule the interview at a time and location that is convenient for you, and I will be asking for your permission to record the conversation. During that time I want to hear your experiences of how you learned to recognize your child's mental illness.

Any questions? **Would you like to participate in this study? Y / N**

Let me get your contact information, and then we'll set a date for the interview.

- Confirm their name.

- Would you prefer to receive the questionnaire by email, fax, or regular mail?
  - E-mail address ____
  - Fax #
  - Mailing Address

- What is the best telephone number for me to reach you?

- What is another number, as a backup?

- Try to select a date, time, and location for the interview, in about a week or two

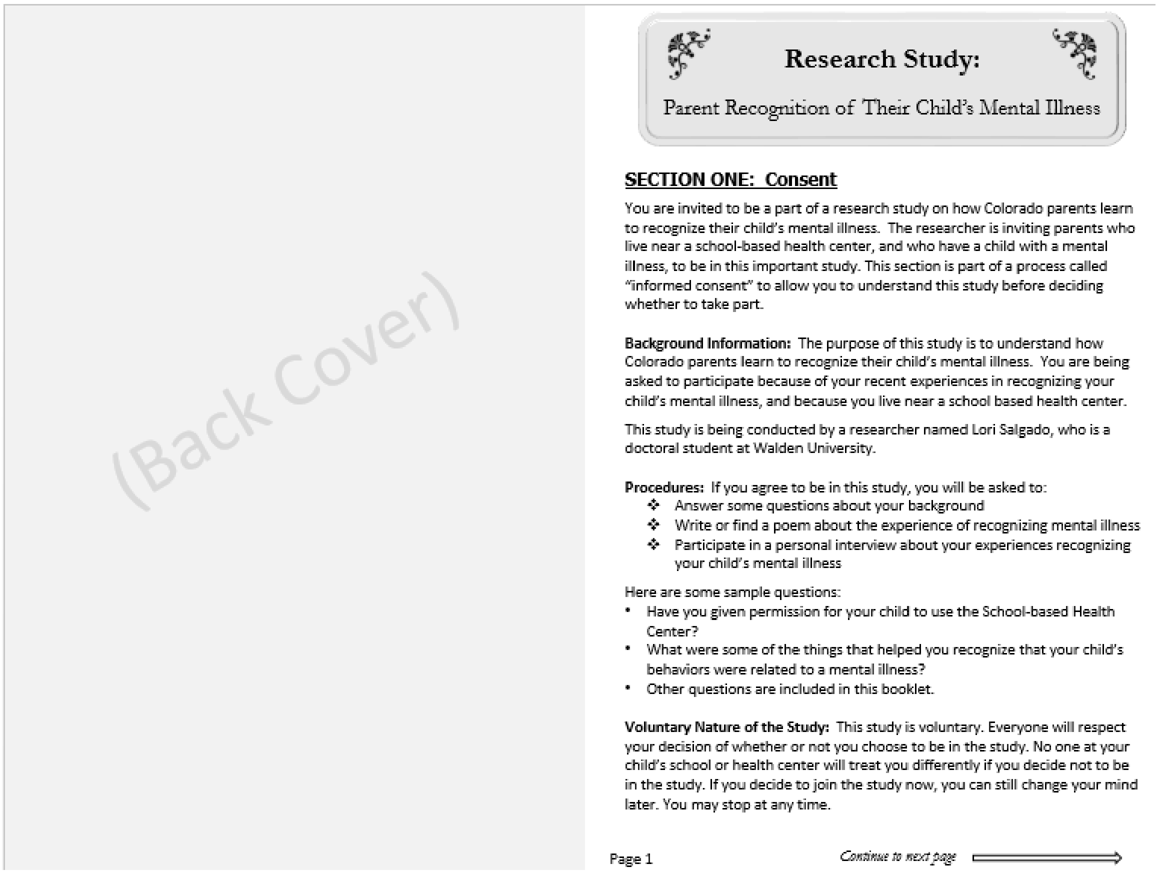
  Date ____

  Time ____________________________

  Location ____

Thank you, and I look forward to meeting you. ☺

Appendix K: Final Pre-Interview Questionnaire



(Back Cover)

Research Study:

Parent Recognition of Their Child's Mental Illness

SECTION ONE: Consent

You are invited to be a part of a research study on how Colorado parents learn to recognize their child's mental illness. The researcher is inviting parents who live near a school-based health center, and who have a child with a mental illness, to be in this important study. This section is part of a process called "informed consent" to allow you to understand this study before deciding whether to take part.

Background Information: The purpose of this study is to understand how Colorado parents learn to recognize their child's mental illness. You are being asked to participate because of your recent experiences in recognizing your child's mental illness, and because you live near a school based health center.

This study is being conducted by a researcher named Lori Salgado, who is a doctoral student at Walden University.

Procedures: If you agree to be in this study, you will be asked to:

- ❖ Answer some questions about your background
- ❖ Write or find a poem about the experience of recognizing mental illness
- ❖ Participate in a personal interview about your experiences recognizing your child's mental illness

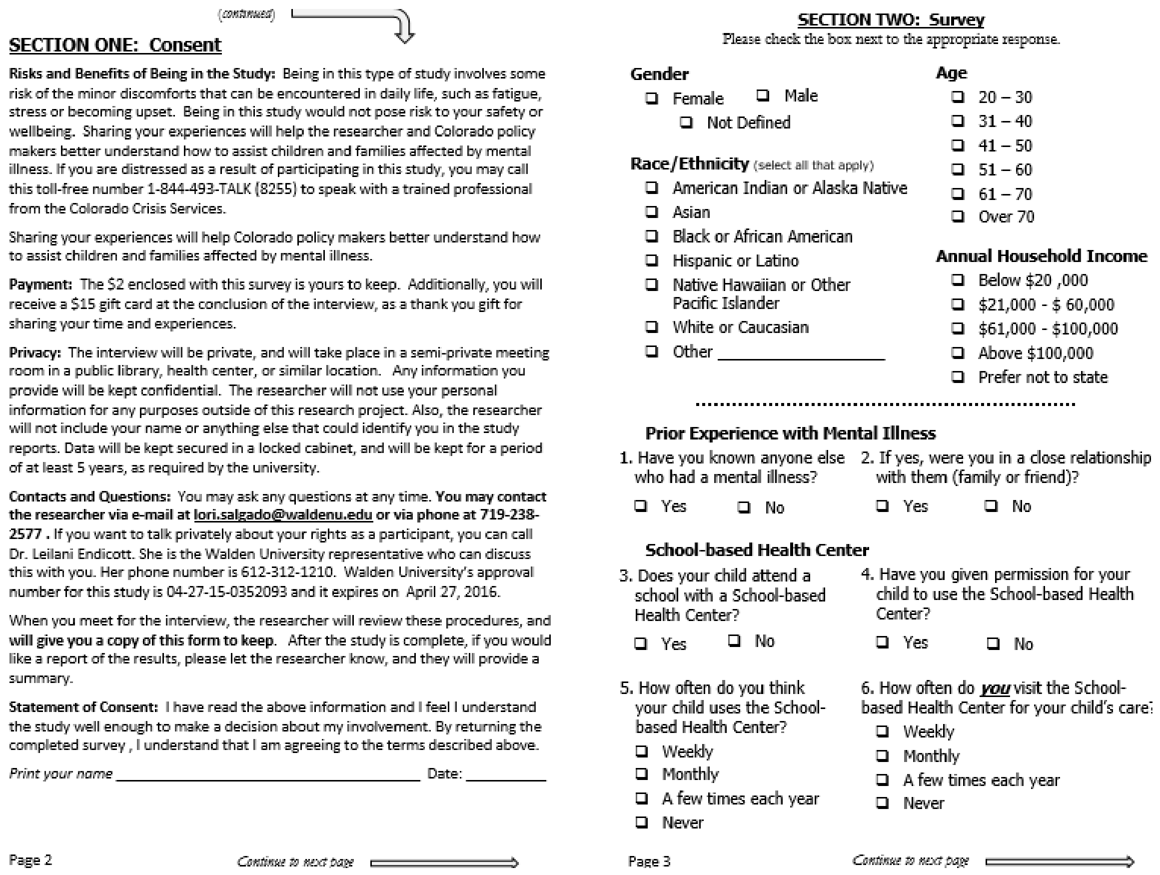
Here are some sample questions:

- Have you given permission for your child to use the School-based Health Center?
- What were some of the things that helped you recognize that your child's behaviors were related to a mental illness?
- Other questions are included in this booklet.

Voluntary Nature of the Study: This study is voluntary. Everyone will respect your decision of whether or not you choose to be in the study. No one at your child's school or health center will treat you differently if you decide not to be in the study. If you decide to join the study now, you can still change your mind later. You may stop at any time.

Page 1

Continue to next page ⟹



(continued)

SECTION ONE: Consent

Risks and Benefits of Being in the Study: Being in this type of study involves some risk of the minor discomforts that can be encountered in daily life, such as fatigue, stress or becoming upset. Being in this study would not pose risk to your safety or wellbeing. Sharing your experiences will help the researcher and Colorado policy makers better understand how to assist children and families affected by mental illness. If you are distressed as a result of participating in this study, you may call this toll-free number 1-844-493-TALK (8255) to speak with a trained professional from the Colorado Crisis Services.

Sharing your experiences will help Colorado policy makers better understand how to assist children and families affected by mental illness.

Payment: The $2 enclosed with this survey is yours to keep. Additionally, you will receive a $15 gift card at the conclusion of the interview, as a thank you gift for sharing your time and experiences.

Privacy: The interview will be private, and will take place in a semi-private meeting room in a public library, health center, or similar location. Any information you provide will be kept confidential. The researcher will not use your personal information for any purposes outside of this research project. Also, the researcher will not include your name or anything else that could identify you in the study reports. Data will be kept secured in a locked cabinet, and will be kept for a period of at least 5 years, as required by the university.

Contacts and Questions: You may ask any questions at any time. **You may contact the researcher via e-mail at lori.salgado@waldenu.edu or via phone at 719-238-2577 .** If you want to talk privately about your rights as a participant, you can call Dr. Leilani Endicott. She is the Walden University representative who can discuss this with you. Her phone number is 612-312-1210. Walden University's approval number for this study is 04-27-15-0352093 and it expires on April 27, 2016.

When you meet for the interview, the researcher will review these procedures, and **will give you a copy of this form to keep**. After the study is complete, if you would like a report of the results, please let the researcher know, and they will provide a summary.

Statement of Consent: I have read the above information and I feel I understand the study well enough to make a decision about my involvement. By returning the completed survey , I understand that I am agreeing to the terms described above.

Print your name ______________________________ Date: __________

Page 2

Continue to next page

SECTION TWO: Survey

Please check the box next to the appropriate response.

Gender

☐ Female ☐ Male
☐ Not Defined

Race/Ethnicity (select all that apply)

- ☐ American Indian or Alaska Native
- ☐ Asian
- ☐ Black or African American
- ☐ Hispanic or Latino
- ☐ Native Hawaiian or Other Pacific Islander
- ☐ White or Caucasian
- ☐ Other ________________

Age

- ☐ 20 – 30
- ☐ 31 – 40
- ☐ 41 – 50
- ☐ 51 – 60
- ☐ 61 – 70
- ☐ Over 70

Annual Household Income

- ☐ Below $20 ,000
- ☐ $21,000 - $ 60,000
- ☐ $61,000 - $100,000
- ☐ Above $100,000
- ☐ Prefer not to state

……

Prior Experience with Mental Illness

1. Have you known anyone else who had a mental illness?

☐ Yes ☐ No

2. If yes, were you in a close relationship with them (family or friend)?

☐ Yes ☐ No

School-based Health Center

3. Does your child attend a school with a School-based Health Center?

☐ Yes ☐ No

4. Have you given permission for your child to use the School-based Health Center?

☐ Yes ☐ No

5. How often do you think your child uses the School-based Health Center?

- ☐ Weekly
- ☐ Monthly
- ☐ A few times each year
- ☐ Never

6. How often do ***you*** visit the School-based Health Center for your child's care

- ☐ Weekly
- ☐ Monthly
- ☐ A few times each year
- ☐ Never

Page 3

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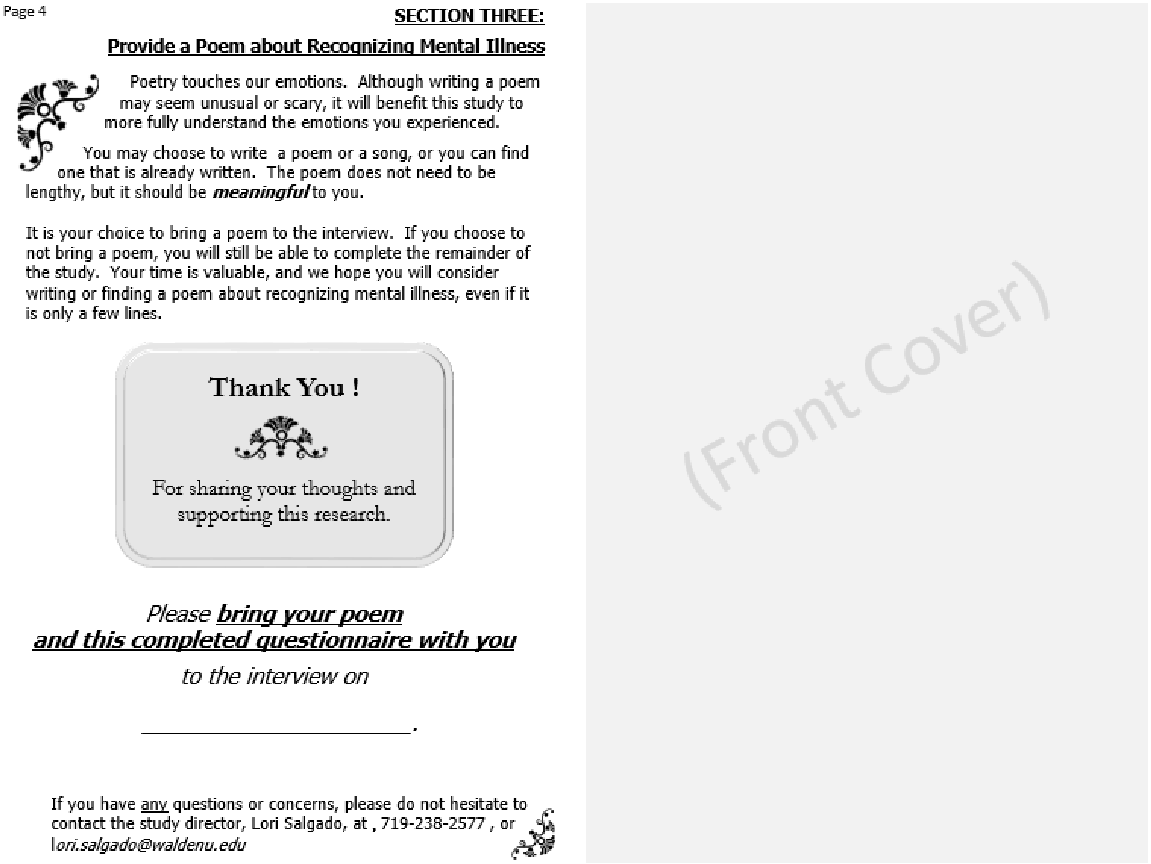


Page 4

SECTION THREE:

Provide a Poem about Recognizing Mental Illness

Poetry touches our emotions. Although writing a poem may seem unusual or scary, it will benefit this study to more fully understand the emotions you experienced.

You may choose to write a poem or a song, or you can find one that is already written. The poem does not need to be lengthy, but it should be ***meaningful*** to you.

It is your choice to bring a poem to the interview. If you choose to not bring a poem, you will still be able to complete the remainder of the study. Your time is valuable, and we hope you will consider writing or finding a poem about recognizing mental illness, even if it is only a few lines.

Thank You !

For sharing your thoughts and supporting this research.

Please ***bring your poem***
and this completed questionnaire with you
to the interview on

______________________.

If you have any questions or concerns, please do not hesitate to contact the study director, Lori Salgado, at , 719-238-2577 , or l*ori.salgado@waldenu.edu*

(Front Cover)

Appendix L: Final Interview Guide

Date: ________________________ ID # _________________

Introduction:

Thank you for your help in this study. My name is Lori Salgado and before we begin the interview I would like to talk to you about your participation in this research study. Its purpose is to understand how parents recognize their child’s mental illness, and what effect a school-based health center may have on that process. I hope to understand this experience from your point of view—to know what you know, in the way you know it.

I want to make sure you understand that participation in this study is voluntary, and you that may stop the interview at any time.

The interview should take about an hour, and we will be reviewing a lot of information about your experiences when you recognized your child’s mental illness, all of which is important for this research project. Since I don’t want to miss any of your comments, would it be alright if our conversation was taped? I will also be taking some notes during the session, but I can’t possibly write fast enough to get it all down.

During this interview, you may feel tired, stressed, or emotional, but beyond that there should be no other risks to your safety or wellbeing. All of your responses will be kept confidential. This means that your interview responses will only be shared with research team members and we will ensure that any information we include in our report does not identify you. Remember, you don’t have to talk about anything you don’t want to and you may ask questions or end the interview at any time.

After we have finished the interview, as a token of gratitude for sharing your time and experiences, I will offer you a choice of a $15 gift card as a thank you.

Are there any questions about what I have just explained?

Are you willing to participate in this interview? Please sign here, and I will give you a copy of the consent form. [Obtain Signature and date; interviewer also signs, and provides a duplicate original of the signed consent form.]

🔓 = Indicates a potential probe

Interview Guide	Notes / Counters
Icebreaker 1. First, tell me a little about yourself 🔓 Where you grew up, some of your hobbies/interests, etc. 2. Now tell me about your child—the one we’ll be referring to most in this interview. 🔓 What are they like? What are their hobbies/interests?	
Awareness 3. I understand that a doctor told you that your child has a mental illness --is that correct? Please share with me your story of how you learned to recognize that your child had this illness. I want to learn not only what	age _______ grade _______ year _______ *Reason(s)* *Behaviors*

happened, but how it all happened and how you felt about it.
🔓 Why does that stand out in your memory?
🔓 Why do you think you noticed that?
🔓 How did that make you feel?
3a. When did you first question that your child's behavior might not be "normal"? [*ask this only if a date or time reference does not emerge in the narrative*]
	Child Characterizations/Attributions
	Attribution to recognition
	___ *Parent's self-realization*
	___ *someone else pointed it out*
	    ___ *family member* _________________
	    ___ *friend*
	    ___ *teacher*
	    ___ *SBHC staff*
	    ___ *pediatrician*
	    ___ *other* _________________________
	      role _____________________________
	Reference to SBHC
	___ *none*
	___ *some*
	___ *specific mention of help*
	___ *specific mention of barrier*
	Reference to school
	___ *none*
	___ *some*
	___ *specific mention of help*
	___ *specific mention of barrier*
	Crisis or Precipitating event

Treatment Decision & Recognition 4. Describe the point when you truly believed your child needed to see a doctor because of their behavior. 🔓 What was it like prior to that understanding? 🔓 What led you to that understanding? 🔓 How did other people respond to that? 🔓 What were other people doing then? 4a. When did this take place? [*ask this only if a date or time reference does not emerge in the narrative*]	

Recognition – Facilitators
5. What were some of the things that helped you recognize that ____'s behaviors were related to a mental illness?
🔓 Why do you think that helped you?
🔓 How did you feel about that?
🔓 Why do you think you noticed that?
5a. To make sure I have this correct—you mentioned that these things helped you recognize that your child's behaviors were related to a mental illness [*List the items they recounted on individual cards, and display the cards*]—is this right?
These are some things that other parents have mentioned helped them [*Display the cards*].
	self ***prompt***
	___ ___ *1. Social network = Family, friend, religious, teacher, school staff, SBHC, pediatrician, law enforcement, other* _________________________
	___ ___ *2. Prior experience with mental illness*
	___ ___ *3. Media = TV, radio, PSA, etc.*
	___ ___ *4. Self-help = books, magazines internet, etc.*
	___ ___ *5. Crisis /Precipitating event*
	___ ___ *6. Other* ____________________
	___ ___ *7. Other* ____________________
	Rank
	Social Network
	  ___ *Family*
	  ___ *Friend*
	  ___ *Teacher*
	  ___ *School Staff* ___________________________
	  ___ *SBHC* _______________________________

Would you please rank order these starting with those things that helped you the most [at the top], to those that were the least help on your ability to recognize [bottom]. 5b. Tell me why you put them in this order.	___ *Pediatrician* ___ *Religious* ____________________________ ___ *Law enforcement* ___ *Other Soc. Net.* ________________________ ___ *Other Soc. Net.* ________________________ ___ *Prior experience with mental illness* ___ *Media = TV, radio, PSA, etc.* ___ *Self-help = books, magazines internet, etc.* ___ *Crisis /Precipitating event* ___ *Other* _______________________ ___ *Other* _______________________
Recognition – Inhibitors 6. Tell me about some of the things that got in the way, or prevented, your recognizing the behaviors as related to a mental illness? 🔓 Why do you think that got in the way? 🔓 How did you feel about that? 🔓 Why does that stand out in your memory? 6a. To clarify, these are the things you mentioned that got in the way, or prevented, your recognizing your child's behaviors as related to a mental illness. [List the items they recounted on individual cards, and display the cards] These are some barriers that other parents have mentioned. [Display the cards]. Please rank order these from strongest barrier to least impact on your ability to recognize. 6b. Tell me why you put them in this order.	***self prompt*** ___ ___ *1. Thought it was normal/ child would outgrow it* ___ ___ *2. Didn't think it was serious enough yet* ___ ___ *3. Didn't think it was medical/ mental illness (personality, etc.)* ___ ___ *4. Environmental explanation of behaviors (parenting, peers, stress, event, etc.)* ___ ___ *5. Religious explanation of behaviors* ___ ___ *6. Thought I could handle it myself* ___ ___ *7. Worried about what people would say / Stigma / Blame* ___ ___ *8. Didn't know where to go/ who to turn to* ___ ___ *9. Husband/ Family didn't think it was necessary* ___ ___ *10. Cost or Accessibility of services* ___ ___ *11. Lack of insurance* ___ ___ *12. Didn't like or believe in doctors* ___ ___ *13. Didn't want medication* ___ ___ *14. No previous experience with mental illness* ___ ___ *15. Other* __________________ ***Rank*** ___ *Thought it was normal/ child would outgrow it* ___ *Didn't think it was serious enough yet* ___ *Didn't think it was medical/ mental illness (personality, etc.)* ___ *Environmental explanation of behaviors (parenting, peers, stress, event, etc.)* ___ *Religious explanation of behaviors* ___ *Thought I could handle it myself* ___ *Worried about what people would say / Stigma / Blame* ___ *Didn't know where to go/ who to turn to* ___ *Husband/ Family didn't think it was necessary* ___ *Cost or Accessibility of services* ___ *Lack of insurance* ___ *Didn't like or believe in doctors*

	___ Didn't want medication *___ No previous experience with mental illness* *___ Other ____________________*
Recognition – Facilitators (Referring to responses from Question 6) 7. What helped you overcome that [particular barrier of] ____? 🔓 Why do you think that helped you? 🔓 If ____ hadn't been there, what do you think would have happened? 7a. How important (1-7) was ____ in helping you overcome that barrier? [Repeat for each facilitator variable cited]	***self prompt*** *___ ___ 1. Social network = Family, friend, religious, teacher, school staff, SBHC, pediatrician, law enforcement, other _________________________* *___ ___ 2. Prior experience with mental illness* *___ ___ 3. Media = TV, radio, PSA, etc.* *___ ___ 4. Self-help = books, magazines internet, etc.* *___ ___ 5. Crisis /Precipitating event* *___ ___ 6. Other ____________________* *___ ___ 7. Other ____________________* *Not Important Moderately Important Extremely Important* *1 – 2 – 3 – 4 – 5 – 6 – 7*
SBHC Now I want to shift a bit and explore what effect the school-based health center may or may not have had on your recognition experience. 8. I understand that your child **does / does not** attend a school with a SBHC … is that correct? [*refer to response from telephone screening*]8a. How important (1-7) was the presence of a SBHC in your awareness that your child's behaviors were not typical? 8b. How important (1-7) was the presence of a SBHC in your ability to recognize your child's mental illness? 8c. How important (1-7) was the presence of a SBHC in your decision to see a doctor about your child's behaviors? 9. If there had not been a SBHC, what effect would that have had on your recognition experience? 🔓 Tell me more about that. 🔓 Can you give me an example? 🔓 Why does that matter? 🔓 If I told you that another SBHC had a policy that required / prohibited ____ [that issue], how would you feel about a policy like that?	*SBHC* *___ none available* *___ wasn't aware of a SBHC* *___ aware but didn't use* *___ specific mention of barrier* *___ specific mention of help* *___ Other ____________________________* *Not Important Moderately Important Extremely Important* *1 – 2 – 3 – 4 – 5 – 6 – 7* *Not Important Moderately Important Extremely Important* *1 – 2 – 3 – 4 – 5 – 6 – 7* *Not Important Moderately Important Extremely Important* *1 – 2 – 3 – 4 – 5 – 6 – 7* *Hypothetical Lack of SBHC* *___ no affect* *___ significant crisis* *___ extended time to recognition / treatment* *___ Other ____________________________*

Poetry 10. Did you bring the poem that you wrote or found? Would you read it to me, or may I read it now? 10a. Thank you for taking the time to do this. Is there anything you want to share about this poem, or about your experiences writing / finding it? 🔓 Request any necessary clarifications 🔓 Probe any themes	
Concluding We're almost finished with the interview, and I only have 2 more questions. 11. Suppose I was a parent who was very concerned about my own child's behaviors, and I came to you—what advice would you offer me? 12. Now that we're at the end of the interview, are there any questions that I did not ask that you think I should have? 🔓 What are they? 🔓 Any others? [Repeat as necessary] ☺	

Conclusion:
This concludes the interview—thank you for sharing your experiences! Do you have any questions for me?

As I review the tapes and my notes, I may need to clarify some things. May I contact you with questions? [*confirm contact data … phone, e-mail, address*]

Please remember that if you feel distress because you recalled these events, you may call the crisis center hotline number.

I appreciate you writing / bringing your poem—this will provide valuable insights. If you decide to write or find another poem, I would be very interested in receiving it.

> [If they did not bring the poem] Although you weren't able to bring a poem today, if you decide to write or find one, I would be very interested in receiving it. May I follow up with you in a week or so about this?

Thank you again for your time [*offer compensation*]. Would you like me to send you a summary of the study results when the study is complete?

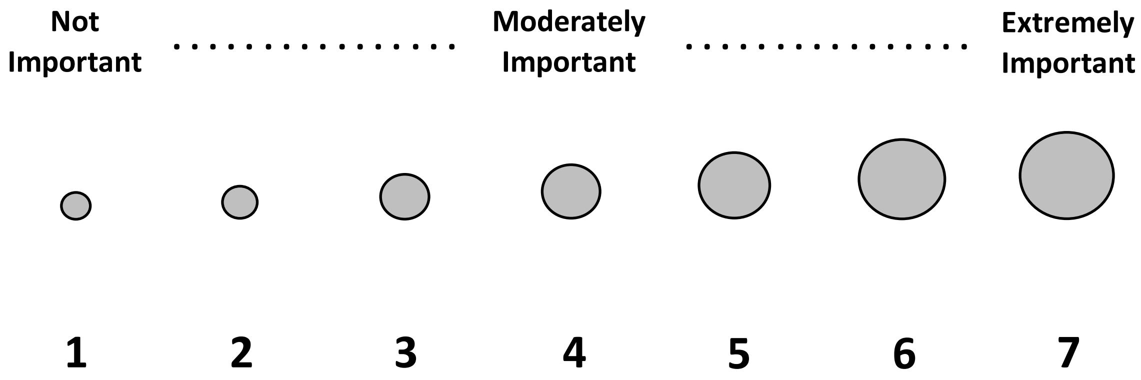
☐ Yes

[if yes, confirm e-mail and/or address—participant's choice of method that will ensure their desired level of confidentiality]

☐ No

Thank you very much. ☺

Rating Card With Scale



Appendix M: Final Screening Questionnaire Guide

Screening Questionnaire

Name: ____________________________________ Date: ________________

Note: If the answer to any of the **numbered questions** *is "no," the inquirer does not meet the eligibility requirements. Inform them, thank them for their time, and ask if they would let others who might qualify know about this opportunity.*

- [Ice breaker] Thank you for inquiring about this research study. I'm curious to know how you found out about it?

- If you don't mind, I have a few questions for you, to make sure you are eligible to participate. Is that alright?

1 Do you care for a child who has a mental illness?
Y / N

- Did a doctor tell you about this illness? Y / N

2. Did the doctor tell you about this illness within the past five years? Y / N

- How old is your child? ________

3. Are you the person who is responsible for making the medical treatment decisions for the child we've been referring to? Y / N

- Does your child attend a school with a School-based Health Center (SBHC?) Y / N

- One aspect of the study includes the use of poetry. Would you be willing to consider composing a poem, or finding a poem or a song that's already been written, that describes your experiences or feelings about your child's mental illness? Y / N

~*~*~*~*~*~*~*~*~*~*~*~*~*~*~**~*~*~*~*~*

You meet the eligibility requirements for this study. ☺

Before I ask for your contact information and we schedule an interview, do you have any questions for me?

[*After questions are answered*] … Let me tell you about the details then. If you have questions at any time, please let me know.

The purpose of this study is to understand the process that parents [caregivers] go through when recognizing that their child has a mental illness. I also hope to learn if the presence of a SBHC has any effect on the recognition process.

The study will take place in two parts—a survey, and then an interview. The survey will be mailed to you, and can be completed at your convenience. It will ask you to reflect on your experiences of recognizing your child's mental illness. Part of this reflection will include writing or finding a poem or song that reflects your experiences or feelings during or about the recognition process. While this may seem unusual, this portion of the research process will be very valuable to the study. Although you may take as much time as you like, I don't expect you to devote more than 30-45 minutes, unless you want to. Other participants reported that they spent between 30 and 45 minutes on this part of the study.

Do you have any questions or concerns before we continue?

The second part of the study involves an interview, and may take up to an hour and a half, although the average length is about one hour. We'll schedule the interview at a time and location that is convenient for you, and I will be asking for your permission to record the conversation. During that time I want to hear your experiences of how you learned to recognize your child's mental illness.

Any questions? **Would you like to participate in this study? Y / N**

Let me get your contact information, and then we'll set a date for the interview.

- Confirm their name.
- Would you prefer to receive the questionnaire by email, fax, or regular mail?
    - E-mail address ____
    - Fax #
    - Mailing Address
- What is the best telephone number for me to reach you?
- What is another number, as a backup?
- Try to select a date, time, and location for the interview, in about a week or two

Date ____

Time _________________________

Location ____

Thank you, and I look forward to meeting you. ☺