Mothers Labeled "Overinvolved": How They Care for Children and Adolescents with Mental Disorders

By

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Dedicated

to

Linda Schaffer

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ABSTRACT

TITLE: Mothers Labeled "Overinvolved": How They Care for Children and Adolescents with Mental Disorders

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The purpose of this study was to develop a grounded theory of how mothers manage the care of children and adolescents with mental disorders, and their perspective about how their care and management of care has been labeled "overinvolved" by mental health professionals. Purposeful sampling was used to select participants for this study. Eight mothers were recruited from a parent-run, state-wide organization for families of children with mental, emotional, or behavioral disorders who met criteria for participation in the study. Criteria for participation were mothers of biological or adoptive children between the ages of birth and 21 years who were diagnosed with a mental disorder classified in the DSM-IV (American Psychiatric Association, 1994). Only mothers who reported having been labeled "overinvolved" (or "overprotective") by a mental health professional on at least one occasion were included. This study used an exploratory research design. The methods of grounded theory were used to investigate mothers' observations of their child's mental disorder and its impact on child behavior, and their understanding of their child's special needs related to the mental disorder, in order to develop a theoretical formulation of their decisions regarding the management of care of their child. Data collection consisted of one audiotape recorded, semi-structured interview with mothers. Two core categories emerged during data analysis. The first core category was the impact of behaviors related to the child's mental disorder on mothers' strategies used to parent and care for their children. The second core category was the relationships between mothers and mental health professionals and between mothers and school personnel. Factors that mothers considered when making decisions regarding the care of their child included the child's safety and the child's special needs. Negative interactions between mothers and mental health professionals were characterized by conflict and disagreement. Positive interactions were characterized by the mental health professionals' ability to listen, validate, and support the mother, in addition to being able to provide an effective treatment for the child. Negative interactions also characterized mothers' relationships with school personnel. Mothers experienced being labeled "overinvolved" negatively. Results and recommendations for theory, clinical practice and research are discussed. The findings from this study have the potential to broaden professionals' perspectives of mothers' behaviors that were previously viewed as "overinvolved" or "overprotective" as an adaptation of mothers' level of care to address their child's specific needs. The findings also can sensitize professionals to the issues and concerns of these mothers leading to interventions which incorporate mothers' care and concerns.

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CHAPTER 1

Statement of Purpose

Background

This study explores the meaning and consequences when mothers are labeled "overinvolved" by mental health professionals during the time they are caring for their child. The study evolved from a critical analysis of widely accepted family therapy theory and my own clinical experiences as a psychiatric-mental health clinical nurse specialist.

Of the 33 million children and adolescents in the United States between the ages of 9 and 17 years, 3.5 million (approximately 11%) of these youngsters have a mental disorder (Center for Mental Health Services, 1997). The total number of children who suffer from mental disorders is estimated to be significantly higher than this; there has been insufficient research on the prevalence rates in very young children ages birth to 8 years.

Children and adolescents with mental disorders tend to be involved with multiple agencies, and often need services over extended periods of time. Parents, most often mothers, are faced with the challenges of managing their child's care.

Family Therapy Theory Perspective

When working with children who have emotional and behavioral disorders, mental health professionals often examine the family environment, examining significant events within the family as well as patterns of interaction that may explain the child's current psychological functioning. As a consequence, parents have been implicated as the etiology for the mental disorders of their children. Certainly in cases of parental neglect and emotional, physical, and sexual abuse, identifying the parent as the source of the child's emotional and behavioral problems is clearly indicated. However, parents of children with mental disorders have also been blamed for being overinvolved, overprotective, or too controlling, and have been viewed as obstructing the autonomy and independence necessary for the continued emotional growth and development of their children.

The perspective of parents as a negative influence on the health of the child is evident in the "psychosomatogenic family model" (Minuchin, 1974, p. 241), a well-known theory among family therapists. This model was "developed in the course of experiences with many families in which the identified patients had widely differing psychosomatic and psychogenic symptoms" (p. 242). Like other symptoms, a psychosomatic symptom can be the expression of family dysfunction in the identified patient. Or, because of particular life circumstances, the symptom may have developed in the identified patient and was then supported and maintained by the family system. Characteristics of this kind of family functioning include enmeshment, overprotectiveness, rigidity, and a lack of conflict resolution. Enmeshment is displayed by family members' overinvolvement and overresponsiveness with one another, in which "protective responses are constantly elicited and supplied" (p. 242). This model views families as rigidly organized, often presenting themselves as not needing or wanting any change in the family.

If it is the child within the family who displays the psychogenic symptomatology, this model suggests that the child's symptoms may be related to the overinvolvement, overresponsiveness, and overprotectiveness by parents and other family members. If the symptoms are to abate, this model suggests that it is the family dynamics or family communication patterns that must change. If the family is resistant to interventions for change, further evidence is provided of the "rigid organization" of the family.

Mental health professionals have also used the conceptual framework of the family life cycle to evaluate what transpires within normal and dysfunctional families. The family life cycle is a developmental concept of family functioning. As a family progresses over time, changes occur in its structure and function, and subsequently affect the way the family interacts (Carter & McGoldrick, 1989).

The family life cycle is a series of developmental stages (e.g., leaving home; single young adults; the joining of families through marriage; the new couple; families with young children; families with adolescents; launching children and moving on; and families in later life). At each stage the family confronts new tasks and challenges and learns new adaptational techniques to successfully transition to the next stage. Failure to adapt to meet these tasks and challenges increases the potential risk of family dysfunction.

Life cycle functions are highly age-related. For example, close physical care and supervision of young children are considered vital to their well-being, whereas increasing autonomy and independence are considered essential for adolescents to successfully transition to young adulthood. Thus, an important aspect of life cycle stages is the change in function required of family members over time.

If parents were to provide close physical care and supervision to an adolescent, they may be viewed as failing to meet the tasks required of a particular stage of development. In this example, the behaviors of the parents may be interpreted as overinvolved and overprotective, impeding any efforts of the adolescent towards growth and independence. Family dysfunction is suggested by the implied inability of the parents to change their behaviors to encourage growth and independence in their adolescent child.

According to Minuchin (1974), "parenting requires the capacity to nurture, guide, and control. The proportions of these elements depend on the children's developmental needs and the parents' capacity" (p. 58). Minuchin also notes that parents cannot protect and guide without being controlling and restricting at the same time.

Using the psychosomatogenic family model and the family life cycle, an over-proportion of nurturance, guidance, control, and protectiveness of parents may contribute to the manifestation of psychogenic symptoms in the child. The over-proportion of these elements as displayed by parents may be further determined depending on the child's location within the family life cycle.

Although these conceptual frameworks can assist mental health professionals in assessing family functioning, these frameworks may also limit how mental health professionals interpret parents' needs and concerns about the child's symptoms and the effects of the child's behavior on the family. What is the extent of our knowledge about parents' experience of caring for their children with emotional and behavioral disorders?

Published research on parents' caregiving experiences of children with mental disorders has been focused on adult children with mental illness (Belcher, 1988; Bulgur, Wandersman, & Goldman, 1993; Chafetz & Barnes, 1989; Chesla, 1989, 1991; Cook, 1988; Eakes, 1995; Greenberg, 1995; Howard, 1994; Pickett, Cook, & Cohler, 1994; Ryan, 1993; Tuck, du Mont, Evans, & Shupe, 1997). In the only publication found to date on family caregiving of younger children, Weiss (1991) examined the stressors of parents caring for children with pervasive developmental disorders. Therefore, our knowledge of parents' caregiving experiences, especially of younger children with mental disorders, has been limited.

Clinical Perspective

Since March, 1995, I have participated as an assistant to the family coordinator of a support group for families of children with emotional, behavioral, and mental disorders. Although fathers have attended this twice monthly support group, it is the mothers of these children who most frequently and consistently have attended these groups. Over time, I observed that a recurring topic of group discussion concerned the mothers' frustration at being labeled "overinvolved" or "overprotective," either by mental health professionals or by school personnel. In these discussions, mothers have judged these labels as unjustifiably critical of their parenting and their relationships with their children. These mothers appeared to have a shared understanding of this experience of labeling and a genuine perplexity as to why mental health and school professionals perceived their mothering as excessive in some way. It has been asked in group, "Why do professionals use that word?," whether that word be "overinvolved" or "overprotective."

As the only mental health professional participant in this family support group, specifically a psychiatric-mental health clinical nurse specialist currently working with children and adolescents in a state psychiatric hospital, I have learned much about the perspective of mothers and the overwhelming challenges of raising a child who has emotional and behavioral difficulties. From my work in psychiatric inpatient settings, I am quite familiar with aggressive children who spit, bite, hit, kick, and throw objects at staff, and with the self-harming adolescent who cuts on his/her body to release emotional pain. Until my participation in this family support group, for some inexplicable reason, I naively had been unaware that some children with these same behaviors also have been cared for by their families at home. Listening to these mothers' stories has taught me about the energy and tenacity of mothers' advocacy efforts in a rigid system, as they work to meet the special needs of their children. I have learned how emotionally, psychologically, and financially burdensome a child's mental illness can be for the family, and how parents who are misunderstood by their extended family may feel due to ignorance about mental illness. And I have learned how hope can be a conflicting and sometimes feared emotion for mothers who have experienced repeated disappointments and heartbreak due to the effects of the mental disorder on a child's ability to function and develop "normally."

There is much information in the literature about how parents, and particularly mothers, of children with mental disorders have been conceptualized as causative agents of their child's mental illness. The impact of these theoretical perspectives of these parents has contributed to our interpretations about parenting of children with mental disorders. This parenting frequently has been interpreted by professionals as negative and pathological to the development of the child and as contributing to the existence and exacerbation of the child's illness.

In contrast, there has been limited information in the literature about the parents' perspectives regarding the effect of mental illness on families and its influence on care and management of care for the ill child. As I listened to the mothers' stories, I found that the parenting challenges they described were unimaginable to me as a mental health professional. Their stories described emotional and behavioral challenges by their ill children that mental health professionals confront within the confines of a locked psychiatric unit that has additional resources of 24-hour nursing staff, psychiatrists and on-call psychiatrists, psychologists, social workers, recreational therapists, and a wide selection of pharmocotherapy. Listening to the mothers' stories helped me appreciate more fully how much control mental health professionals have due to the vast resources available to them when working with children and adolescents with mental disorders. I also was able to realize how profoundly isolated and alone mothers can be in the care and management of their child. Last but not least in these realizations, the boundaries of the mental health professional's relationship are time-limited, unlike the mother-child relationship. Mothers will continue to experience the challenges of their child's mental illness for years to come.

Specific Aims

The purpose of this study was to develop a grounded theory of how mothers manage the care of children and adolescents with mental disorders, and their perspective about how their management of care has been labeled "overinvolved" by mental health professionals. This study addressed the following questions:

1. What factors do mothers consider when making decisions regarding the care of their child or adolescent with a mental disorder?

2. How do mothers describe the situations in which they were labeled "overinvolved" and what that experience was like for them?

3. What do mothers describe as the impact of being labeled "overinvolved" on their relationships with mental health professionals?

4. What do mothers describe as consequences of being labeled "overinvolved" on their parenting behavior?

CHAPTER 2

Review of Literature

Introduction

Literature was reviewed with the purpose of stimulating and enhancing theoretical sensitivity. Theoretical sensitivity is a term associated with grounded theory. Strauss and Corbin (1990) provide the following definition of theoretical sensitivity:

> Theoretical sensitivity refers to a personal quality in the researcher. It indicates an awareness of the subtleties of meaning of data. One can come to the research situation with varying degrees of sensitivity depending upon previous reading and experience with or relevant to an area. It can also be developed further during the research process. (p. 41)

In grounded theory studies, theoretical sensitivity "is the ability to recognize what is important in data and to give it meaning" (Strauss & Corbin, 1990, p. 46). As one source of theoretical sensitivity, literature can provide information that "sensitizes" the researcher to what is going on with the phenomenon under study (Strauss & Corbin, 1990).

The purpose of this study was to develop an empirically grounded theory about how mothers manage the care of children and adolescents with mental disorders and from their perspective, how their management of care has been labeled "overinvolved" by mental health professionals.

Parents' Caregiving Experiences of Children with Mental Illness

Published research on parents' caregiving experiences with children with mental illness has focused on caregiver burden (Belcher, 1988; Bulgur et al., 1993; Greenberg, 1995; Pickett et al., 1994), parents' caring practices of children with schizophrenia (Chesla, 1991), parents' illness models of schizophrenia (Chesla, 1989), parents' chronic sorrow (Eakes, 1995), stressors of parents caring for children with pervasive developmental disorders (Weiss, 1991), and descriptions of parents' caregiving experiences of adult children with schizophrenia (Howard, 1994; Ryan, 1993; Tuck et al., 1997). With the exception of Weiss (1991), these studies focused on parents' caregiving experiences with their adult children.

These studies were parent-focused and explored the impact of the child's mental illness on the parent as caregiver. None of these studies examined the impact of parental caregiving on the child, the child's mental illness, or the child's treatment. All used convenience samples.

Parents' caregiving experiences of adult children. Most of the parental caregivers described in these studies were mothers of adult sons diagnosed with schizophrenia or schizoaffective disorder. The majority of studies reported fairly consistent findings regarding parental caregivers and their caregiving experience.

Parents focused their care based on how they understood the illness. Parents' understanding of the illness shaped what they saw, what they did, and what they wished to have done for their children (Chesla, 1989). Much of their understanding of the illness was determined by the negative effects of the mental illness on the adult child's ability to function autonomously and independently, with many adult children unable to achieve normative life-span transitions, and unable or unwilling to leave the parental home (Belcher, 1988; Bulgur et al., 1993; Chesla, 1989, 1991; Eakes, 1995; Howard, 1994; Pickett et al., 1994; Ryan, 1993; Tuck et al., 1997).

Consequences of the adult child's continuing dependence and need for supervision forced aging parents to adapt their parenting practices to a level of care normally expected for a younger child. Themes such as "unending caregiving responsibilities" (Eakes, 1995), "lifelong caregiving" (Howard, 1994), "a lifetime of mothering" (Ryan, 1993), and "endless caring" (Tuck et al., 1997) are reflected in these studies. Parents' experiences are characterized by a lack of respite care, impact on family life and on other family members, excessive demands on time and energy, and financial drain (Belcher, 1988; Eakes, 1995; Howard, 1994; Pickett et al., 1994; Ryan, 1993; Tuck et al., 1997). Although parents may have encouraged and expected age-appropriate goals and behavior from their adult children, parents simultaneously were faced with regressive behavior and the realization that their children were ill, vulnerable, and bound by certain limitations (Ryan, 1993). Examples of parents' struggles with their adult children around basic self-care included waking the ill adult child each morning, reminding him or her to change clothes and maintain proper hygiene regularly, and urging completion of household chores, such as making the bed (Pickett et al., 1994).

The severe and persistent symptoms of chronic mental illness that negatively affected the ability of the adult child to function independently resulted in parents' frequently expressed feelings of anger, anxiety, confusion, distress, fear, frustration, grief, helplessness, resentment, sadness, sorrow, and uncertainty (Belcher, 1988; Bulgur et al., 1993; Chesla, 1989, 1991; Eakes, 1995; Howard, 1994; Pickett et al., 1994; Ryan, 1993; Tuck et al., 1997). Such feelings were a response to a situation that involved an altered life trajectory for both the adult child and parent.

In contrast to the findings of the majority of the studies reviewed, Greenberg (1995) studied 105 mothers with an average age of 66 years (age range of 55 to 89 years) who were living with an adult child with mental illness, with an average age of 35.6 years (age ranging from 22 to 58 years). Data from this study indicated that as mothers approached and entered their retirement years, some adult children with mental illness could become family resources by providing assistance and support to their mothers. Examples of assistance and support included doing household chores, providing news about family and friends, and providing companionship. Greenberg concluded that "with the effort focused on helping such clients establish independence from their families, clinicians may fail to recognize the contributions that some clients make to their families" (p. 421).

Parents' caregiving experiences of younger children. In the only published research found to date on parents' caregiving experiences of younger children with mental illness, Weiss (1991) examined the particular stressors that challenge parents who care for children with pervasive developmental disorders.

This study involved a subsample of family caregivers who were part of a larger study examining the social support needs of families caring for psychiatric patients of varied diagnoses and age. Parents were recruited from public and private mental health agencies and through day care facilities. This subsample included 20 parents who had primary responsibility for a child living at home, who was diagnosed with pervasive developmental disorder that met the Diagnostic and Statistical Manual of Mental Disorders, third edition, revised (DSM-III-R) criteria for codes 299.00, Autistic Disorder, and 299.80, Pervasive Developmental Disorder Not Otherwise Specified (NOS). Half of the children were diagnosed with Autistic Disorder and the other half with Pervasive Developmental Disorder NOS. Two of the children also had Tourette's Disorder and others also were classified with mental retardation, motor skills disorder, language and speech disorder, and attention-deficit hyperactivity disorder. Most of the children were involved in some day treatment or care facility at certain times during the week.

Parents ranged in age from 27 to 65 years, with a mean age of 48.3. Ninety-five percent were female and Anglo-American. Seventy percent were married and 65% were employed. All but three of the parents considered their incomes to be adequate or more than adequate to meet family needs. They averaged 14.8 years of education. Their time in a caregiving role since the diagnosis of the child varied from 8 months to 22 years.

The mean age of the children was 12, with a range from 7 to 28 years. The oldest child originally had been diagnosed with the disorder at age 6. Seventy-five percent of the children were male.

Data were collected in a two-step format. The first step involved a brief semi-structured interview and the second step involved parents' ratings of 21 possible stressors. For step one, parents were asked to identify and describe the three stressors that affected them the most. These interviews were audiotaped and later transcribed verbatim for content analysis of the stressors.

Six major themes of stressors were identified from content analysis of the interview data and were rank-ordered based on frequency of identification. The first theme, "Arranging for/Collaborating with Professional and Support Services," was common to all 20 parents. Examples of professional services included psychiatrists, psychologists, pediatricians, and special education teachers. Support services included daycare centers, baby sitters, or respite workers. Stressors from professional services were related to receiving misinformation about the etiology and prognosis of the child's disorder, only later to have the diagnosis or the child's potential clarified. Parents also received inadequate or inappropriate information regarding concrete strategies to manage the child's behavior. Stressors from support services were related to a lack of competent and trustworthy sources to provide supervision for the child and some respite for the parent.

The second theme, "Strains within the Family," was mentioned by all but 2 parents. Disruption of normal family life as a result of the child's illness contributed to family conflict and unhappiness. Marital/partner discord resulted from differing opinions regarding appropriate treatment or placement for the child. Siblings of the ill child were reported to act out to get attention.

The third theme, "Stigmatization from Child's Condition," included feelings of embarassment and shame from the negative reactions parents encountered from others, such as neighbors and work associates. Six parents also experienced feeling blamed by professionals for their child's illness.

The fourth theme, "Dealing with the Child's Behavior," related to their child's behavior that was unpredictable and uncontrollable and a cause of constant anxiety. Slightly more than half of the parents noted this as a major stressor.

The fifth theme, "Concerns about Parent's Own Mental Health," related to parents' recurrent feelings of intense anger, guilt, depression, or anxiety. Over half of the parents reported being in psychotherapy at some point since the child's diagnosis for their own mental health needs.

The sixth theme was "Fears Regarding the Child's Future." The largest category under this theme was fear of the potential need for institutionalization if the child's behavior became too uncontrollable. Another category was related to the parent's eventual death and the concerns as to whether other family members would assume responsibility for the child. Specific developmental issues, such as the potential problems related to the child's emerging sexuality, were also mentioned as stressors.

For step two, parents reviewed and rated the severity of stress of 21 possible stressors on a 7-point Likert scale, ranging from 0 = no stress at all to 6 = the worst possible stress. These 21 stressors were thought to reflect the spectrum of caregiver stressors which had been identified from clinical and research activities to date.

Mean scores and standard deviations from the second step of data collection indicated that 10 of the 21 pre-established stressors rated by the parents were viewed as causing severe stress. These severe stressors included: insufficient information to care for the child, constant need for supervision, difficulty getting or using professional help, insufficient ability to cope with the child's special problems or behavior, household disruption, problems with communication ability of the child, lack of relief/respite for physical time demands of caregiving, special arrangements that need to be made for the child, unpredictability of child's progress, and interference with family life. "Problems with the emotional and mental state of the child" was the only item achieving a mean score that reflected extreme stress for the parents. None of the demographic variables (age of child, age of parent, years of caregiving, marital status of the parent, his/her years of education, and the adequacy of the family's income) showed any significant relationship to the degree of stress reported by the parents.

This study provides important information about the stressors involved in caring for children with mental disorders with a mean age of 12, suggesting that the focus is on younger children as opposed to adult children. With this suggested focus on younger children, it is confusing as to why Weiss (1991) extended the age range to 28 years. She does explain that the oldest child included in the study was originally diagnosed with the disorder at age 6; however, at age 28, this child is an adult child whose care may be influenced by different developmental concerns.

The purpose of the second step of data collection, in which parents rated the severity of stressors thought to reflect the spectrum of caregiver stressors which had been identified from clinical and research activities to date, is unclear. This quantitative data may have been required of the larger study examining the social support needs of families caring for psychiatric patients of varied diagnoses and age. However, given the purpose of this study, which was to identify the particular stressors that challenge parents who care for children with pervasive developmental disorders, it would seem that the first step of data collection, involving a brief semi-structured interview in which parents were asked to identify and describe the three stressors that affected them the most, would have been sufficient.

Perspectives on Parenting, Parental Overprotection, and Mothers

Parenting. According to Gellerstedt and leRoux (1995), the tasks of parenting include: providing stability, nurturance, safety, structure; emotional and physical space to facilitate the child's maturation and development; and the enculturation of codes of behavior, beliefs, morals, and rituals (p. 74). In a review of approaches to the systematic assessment of parenting, Mrazek and colleagues (Mrazek, Mrazek, & Klinnert, 1995) stated, "It is self-evident that under usual circumstances, good parenting contributes to the development of normal children" (p. 272). They also noted that, "Throughout the history of psychology, the quality of parenting has been a central component of most child developmental theories. Similarly, poor parenting has been considered to be a risk factor for the development of psychopathology throughout the history of child psychiatry" (p. 272).

The assessment of parenting has typically included five key dimensions. These dimensions are (a) emotional availability, (b) control, (c) psychiatric disturbance, (d) knowledge base, and (e) commitment (Mrazek et al., 1995, p. 274). Emotional availability refers to the degree of emotional warmth, e.g., warmth versus aloofness, that parents demonstrate. Control refers to the degree of parents' flexibility and permissiveness. Psychiatric disturbance refers to the presence, type, and severity of overt disorder. Knowledge base refers to parents' understanding of basic child care principles and children's emotional and physical development. Commitment refers to the degree of time and energy that parents are willing to make to enhance the development of their children. According to Mrazek et al., parenting remains an extraordinarily difficult construct to measure. There is no generally accepted approach for defining the quality of parenting, other than the traditional clinical evaluation based on systematic interviews with both parents and their children combined with observations of family interactions.

Mrazek et al. (1995) believe that one problem in the development of parenting measures has been due to the "persistent defensiveness on the part of parents" (p. 273) because "parents have rejected attempts to focus on their shortcomings" (p. 273). The "persistent defensiveness" of parents is understood to be their reaction to what has now been accepted as the "unfair parent-blaming" attributions generated by psychodynamic clinicians to explain biologically-based disorders. Examples of these parent-blaming attributions have been the "refrigerator parents" of infantile autistic children who were believed to play a causal role in the development of their child's severe social and emotional difficulties, and the "schizophrenogenic mothers" believed to be primarily responsible for the development of schizophrenia in their children. It was only when these mental disorders were understood to have neurobiological origins, that these attributions were viewed as incorrect and unfair to the parents of these severely ill children (Mrazek et al., p. 273).

Parental overprotection. According to Thomasgard and Metz (1993), "the dimensions of parental overprotection have never been fully clarified, with such terms as overindulgent, oversolicitous, overprotective and overanxious parents being used interchangeably" (p. 67). Because the mothers in the family support group have also interchanged the terms "overinvolved" and "overprotective," parental overprotection is examined, using Thomasgard and Metz's review of these parenting behaviors.

Parental overprotection has been viewed as both an indulgent parent-child relationship and an overprotective parent-child relationship. An indulgent parent-child relationship is characterized by "a guilty, anxious parental attachment to the child" (Thomasgard & Metz, 1993, p. 68). As the child becomes more independent, setting limits becomes more difficult, and anxiety and unresolved feelings of guilt or grief continue to recur. Guilt may at times be replaced by anger, leading the parent to suddenly become punitive towards the child, shifting from overly indulgent to overly controlling and demeaning behaviors. Prescription for these parenting behaviors is to "understand parental anxiety surrounding limit setting and to help the parent develop more consistent and effective behavioral strategies to use with the child" (Thomasgard & Metz, p. 68).

In contrast to an indulgent parent-child relationship, an overprotective relationship is characterized by "a parent who: 1) is highly supervising and vigilant, 2) has difficulties with separation from the child, 3) discourages independent behavior and 4) is highly controlling" (Thomasgard & Metz, 1993, p. 69).

Parental overprotection has been viewed as a "relationship disorder," in which a normal developmental process, such as the increasing autonomy of the child, is "excessively or persistently restricted" by the parent (Thomasgard & Metz, 1993, p. 73). According to Thomasgard and Metz, retrospective studies have related parents' controlling overprotective behaviors to adult outcomes of dysthymia and anxiety disorders in the overprotected child (p. 68).

Although the mothers in the family support group have experienced the label of "overinvolvement" or "overprotection" as unjustifiably critical of their parenting and their relationships with their children, these mothers also have acknowledged the legitamacy of these labels. For example, one mother from the group said if her relationship with her 14-year-old "normal" son was described as "overinvolved," she would consider thinking about how she responds to him and whether her responses need to be modified to support his increasing autonomy. However, this mother would be very angry if she was described as "overinvolved" with her 10-year-old son who sustained a traumatic brain injury when he was 5 years old. The traumatic brain injury seriously affected her son's social and cognitive level of functioning resulting in the need for adaptations in the school setting. This mother's experience has been that he will not receive needed services, such as increased structure and supervision, if she does not advocate for her son.

<u>Mothers.</u> Mothers have been blamed in the literature for the psychopathology of their children. There have been the "schizophrenogenic mothers" whose behaviors were believed to cause schizophrenia in their children (Wahl, 1989). The first empiric research study on parental overprotection focused on mothers of children seen at a child guidance clinic (Thomasgard & Metz, 1993). Evidence of "mother-blaming" can be found in Caplan and Hall-McCorquodale's (1985) content analysis of nine clinical journals. In 125 articles reviewed, a total of 72 different kinds of psychopathology were attributed to mothers. Some of the problems identified in the literature included, "aggressiveness, agoraphobia, anal obsession, anorexia nervosa, anxiety, arson, bizarre behavior, delusions, dependence, depression, homosexuality, hyperactivity, incontinence, ineducability (intellectual), minimal brain damage, moodiness, need to be anally penetrated, phobias, poor concentration, poor language development, schizophrenia, severe mental handicap, suicidal behavior, and ulcerative colitis" (p. 348).

As previously mentioned, the quality of parenting is a central component of most child developmental theories (Mrazek et al., 1995). Mothers' historic role in the family is to have primary responsibility for childrearing (Sommerfeld, 1989). Therefore, from the theoretical perspective of child development, the quality of parenting is primarily about the quality of mothering and its relationship to the developmental outcomes of children. One is unable to discuss children without involving mothers and what they do or do not do in regards to their children. This may explain the historic focus on mothers when examining the normative or pathologic development of children.

Summary

The majority of published research on parents' caregiving experiences of children with mental illness has focused on parents' caregiving experiences with their adult children. Child development theories have focused on the quality of parenting with the understanding that good parenting contributes to the development of normal children and poor parenting is considered a risk factor for the development of childhood psychopathology. Parental overprotection has been viewed as a "relationship disorder," in which a normal developmental process, such as the increasing autonomy of the child, is "excessively or persistently restricted" by the parent (Thomasgard & Metz, 1993, p. 73). Finally, literature has focused on mothers, who historically have had primary responsibility for childrearing, when examining the normative or pathologic development of children.

Mental illness, now understood to be genetically and neurochemically influenced, can affect a child's normal developmental process. Therefore, labeling mothers' parenting as "overinvolved" and implicated in their child's illness is suspect. By examining mothers' perspectives about the way mental illness affects how they care for their children and the impact of being labeled, it is hoped that this may lead to greater sensitivity and understanding of their decisions regarding their children's care.

CHAPTER 3

Methods

The purpose of this study was to develop a grounded theory of how mothers manage the care of children and adolescents with mental disorders, and their perspective, about how their management of care was labeled "overinvolved" by mental health professionals. This study addressed the following questions:

1. What factors do mothers consider when making decisions regarding the care of their child or adolescent with a mental disorder?

2. How do mothers describe the situations in which they were labeled "overinvolved" and what that experience was like for them?

3. What do mothers describe as the impact of being labeled "overinvolved" on their relationships with mental health professionals?

4. What do mothers describe as consequences of being labeled "overinvolved" on their parenting behavior?

For the purposes of this study, "manage" was defined as "to handle, direct, govern, or control in action or use" (Webster's Encyclopedic Unabridged Dictionary of the English Language, 1989, p. 869). "Child" refers to a child or adolescent between the ages of birth and 21 years. "Mental disorder" entailed any diagnosable mental, emotional, or behavioral disorder of sufficient duration to meet diagnostic criteria specified within the Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM-IV) (American Psychiatric Association, 1994) and resulted in impairment which substantially interfered with or limited the child's role or functioning in family, school, or community activities. Because of the common interchangeable use of the terms, "overinvolved" and "overprotective" (or "overinvolvement" and "overprotection"), both terms were understood to have similar meaning. "Overinvolved" and "overprotective" are descriptions of how mothers managed the care of their child in which the level of care was perceived as excessive and beyond the developmental needs of the child.

Design

This study used an exploratory research design and the methods of grounded theory. Grounded theory is a qualitative research method used to generate an empirically grounded theory about a phenomenon through a systematic set of procedures. Developing theory implies interpreting data because the data must be conceptualized and the concepts related to each other to formulate an explanation of reality. The purpose of the theoretical formulation is to explain that reality and provide a framework for action (Strauss & Corbin, 1990). Thus, this study used methods of grounded theory to investigate mothers' observations of their child's mental disorder and its impact on child behavior, and their understanding of their child's special needs related to the mental disorder, in order to develop a theoretical formulation of their decisions regarding the management of care of their child.

Sample

Purposeful sampling was used to select participants for this study. By deliberately choosing sites, persons, and documents, one looks purposely for data bearing on categories, their properties, and dimensions (Strauss & Corbin, 1990, p. 183). Participants were recruited from the Oregon Family Support Network, a parent-run, state-wide organization for families of children with mental, emotional, or behavioral disorders. A letter (Appendix A) was sent to Oregon Family Support Network requesting assistance in recruiting participants for the study. Potential participants were referred to the investigator by the Oregon Family Support Network and initially were contacted by telephone by the investigator.

Criteria for Participation

Criteria for the selection of participants for this study were mothers of biological or adoptive children between the ages of birth and 21 years who were diagnosed with a mental disorder classified in the DSM-IV (American Psychiatric Association, 1994). Restricting children's ages to under 21 years allowed a focus on issues related to minor children. Only mothers who reported having been labeled "overinvolved" (or "overprotective") by a mental health professional on at least one occasion were included. Mothers were English-speaking, and lived within a 50-mile radius of Portland, Oregon. The mother had to have had legal and custodial responsibility for the care of their child, and the mother may or may not have been living with the child at the time of the study.

Demographic Data Analysis

Demographic data was analyzed using descriptive statistics to calculate frequencies, means, and percentages.

Sample Characteristics

From fourteen mothers referred to the investigator by the Oregon Family Support Network, eight mothers met criteria for participation in the study. Sample characteristics of the mothers are summarized in Table 1. The mothers were older at the time of interview: one mother was in her thirties, 5 mothers were in their forties, and 2 were in their fifties. Half of the mothers were currently married/partnered, with 1 of those separated; half of the mothers were divorced (n = 4; 50%). All except one of the mothers were Caucasian, and the exception identified herself as "Other." The women were well-educated. Of their highest education level, 1 mother had a high school diploma, 3 mothers had attended some college, 3 mothers had a college degree, and 1 mother had some graduate education. Total annual household income reflected a broad range from $6,000 to $50,000 and over.

Of the eight children with mental disorders, six were daughters. Ages of the children ranged from 15 to 20 years, with a mean age of 17.8 years, at the time of the interviews. Four of the children were diagnosed with bipolar disorder, one child had major depressive disorder, two children were diagnosed with autistic disorder, and one child had attention-deficit/hyperactivity disorder. The children's length of involvement with mental health services ranged from 4 to 15 years, with a mean 8.4 years of involvement. Sample characteristics of the children are summarized in Table 2.

Table 1. Characteristics of the Mothers

Variable	n	%
Age in Years		
30 - 39	1	13
40 - 49	5	63
50 - 59	2	25
Marital Status		
Married/Partnered	3	38
Separated	1	13
Divorced	4	50
Ethnicity		
White	7	88
Other	1	13
Highest Education Level		
High School Diploma	1	13
Some College	3	38
College Degree	3	38
Some Graduate Education	1	13
Annual Income		
\$6,000 - \$9,999	2	25
\$10,000 - \$14,999	1	13
\$15,000 - \$19,999	1	13
\$20,000 - \$29,999	2	25
\$50,000 and over	2	25

Mean age = 45.9

Table 2. Characteristics of the Children

Variable	n	%
Age in Years		
15 - 15.9	2	25
16 - 16.9	0	--
17 - 17.9	2	25
18 - 18.9	1	13
19 - 19.9	0	--
20 - 20.9	3	38
Sex		
Male	2	25
Female	6	75
Diagnosis		
Major Depressive Disorder	1	13
Bipolar Disorder	4	50
Autistic Disorder	2	25
Attention-Deficit/Hyperactivity Disorder	1	13
Length of Involvement with Mental Health Services		
4 - 4.9 years	1	13
5 - 5.9 years	1	13
6 - 6.9 years	1	13
7 - 7.9 years	1	13
9 - 9.9 years	1	13
10 - 10.9 years	2	25
15 - 15.9 years	1	13

Mean Age = 17.8 Mean Length of Involvement with M. H. Services = 8.4

Data Collection Procedures

Interviews were scheduled at times of mutual convenience for the participant and the investigator. Individual in-depth interviews were conducted with each participant at her home or at a quiet, convenient location of her choice. Participants were informed that they would be interviewed at least twice and, at most, three times (Appendix B). The purpose of the second and, if necessary, third interviews was primarily to clarify statements from the first interview. Because of the clarity of the data from the first interviews, it was not necessary to conduct second and third interviews. All participants were contacted to inform them that further interviews would not be necessary. During that second contact, information was shared with all participants regarding the qualitative results and analysis. Interviews lasted between one to two hours. All interviews were audiotape recorded and then transcribed.

Instrumentation

A questionnaire (Appendix C) was given to each participant to gather demographic information. Maternal characteristics included age, marital status, ethnicity, educational level and income. Child characteristics included age, sex, diagnosis, and length of involvement with mental health services following the initial interview.

The interview guide (Appendix D) was derived from the purpose of this study. Open-ended questions were used to obtain participant responses. The initial interview guide was intended to provide a beginning focus and was considered for revision as data were analyzed, compared, and concepts emerged. In grounded theory method, the emergent theory helps to guide the data collection.

Data Management

All individual in-depth interviews were audiotape recorded and transcribed by the investigator. To maintain the confidential nature of the interviews, true names were not transcribed. All identifying information was removed from the transcripts. For example, true names of the participants and mental health providers were masked in the transcripts and only the investigator had knowledge of this information. All identifying data collected during interviews, such as demographic information, were kept separate from the transcripts.

Ethical Considerations

Protection of Human Subjects

This study was conducted with review and approval by the Oregon Health Sciences University Institutional Review Board. At the time of data collection, participants were given sufficient time to read the consent form (Appendix B) and to ask questions about the study prior to signing. All participants were given a copy of the signed consent form before the interview. To maintain the confidential nature of the interviews, (true) names were not transcribed. All identifying information was removed from the transcripts.

Potential Risks and Benefits

Participants were advised at the time of informed consent that any suspected child abuse must be reported to the appropriate authorities according to Oregon Law. Participants were advised that if they experienced discomfort during the interview they may stop the interview at any time, ask to continue the interview at another time, agree to only one interview, choose not to answer any question, or withdraw completely from the study. Benefits included the opportunity to talk with a person interested in listening to their experiences of caring for a child with a mental disorder, and their perspective about how their management of care was labeled "overinvolved" by mental health professionals.

Qualitative Data Analysis

Interview data was analyzed according to the grounded theory procedures and techniques described by Strauss and Corbin (1990). Data analysis consisted of three major types of coding. These were (a) open coding, (b) axial coding, and (c) selective coding (p. 58).

Strauss and Corbin (1990) define open coding as "the process of breaking down, examining, comparing, conceptualizing, and categorizing data" (p. 61). Categorizing is the "process of grouping concepts that seem to pertain to the same phenomena" (p. 65). Open coding may be approached through "line-by-line analysis," "sentence or paragraph," or "an entire document" (p. 73).

Some of the examples of open codes used to conceptualize and categorize the data were "Behaviors," "Mothers' Care," and "Understanding Child's Needs." This investigator approached open coding through sentences and paragraphs. Examples of sentences and paragraphs that were categorized as "Behaviors" included the following:

Example 1:

And then she started all of a sudden when she got angry and one of the first times finding her, she's locked herself in the bathroom, and she wouldn't open the door, and wouldn't open the door, and finally she did after she cut her toe with a razorblade, and so it was just like the beginning of self-mutilation. She would find sharp things. Her forte was to scratch her arms when she was real upset.

Example 2:

Oh she would, you know, she would spit in my face and hit me, and hit her sister, and you know that kind of thing.

Example 3:

And I'd list some of the things he did, like sticking his hands on . . . my mother had a gas oven kind, you know the burners, he'd stick his hands on them when they were on and he blistered his fingers, and he'd laugh about it. It was like funny, "Ha ha."

Examples of sentences and paragraphs that were categorized as "Mothers' Care" included the following:

Example 1:

Well, on day-to-day, I was very worried. In fact at that time, I did utilize some of my daughters and this sounds just absolutely awful, doesn't it, but the oldest, gosh, um, I'm trying to, sometimes some of them would be home 'cause she really is into a situation where someone needed to be there all the time.

Example 2:

So you know, they told me to take the most important thing from her, as discipline, which was the phone, so consequently, you know, when I wouldn't let her have the phone, she would break the phones. And that sort of thing, you know, it's not like I wasn't disciplining her, I was tough on her. I mean I can even remember physically restraining her. Being taught how to physically restrain her.

Example 3:

I'd spend so much time teaching him stuff, like how to, leave the damn windshield wipers alone, or quit doing that, or with his hands--he would do his hands thing, and I taught him how to get a ball and stick his hands in his pocket and squeeze the ball. You know, try to do something a little better with his hands.

Examples of sentences and paragraphs that were categorized as "Understanding Child's Needs" included the following:

Example 1:

I would see things that I thought would label this girl as a manic-depressive because she had such severe mood swings.

Example 2:

And she has a profound problem with depression that is a constant thing. And she fights it as it comes upon her and then leaves. And that is not like most kids her age. And that is her biggest battle. The depression is her biggest battle. She seems to be pretty OK with the manic phase, but the depression is the one that totally weighs on her life and she has a very clear, sharp realization of it, now. And that's her biggest battle and she'll tell you that quite straight and clear. And so, she told me recently that she was completely and utterly exhausted with her constant battle with depression. But she fights it and that's good. And it's when she's not fighting it, that everyone has to worry, you know, and that she needs help the most. But she needs help even when she's fighting it. You know she needs encouragement and that kind of thing.

Example 3:

I'd ask, "He needs social skills training when he's older to learn how to communicate, interact . . .," and their idea of that was to take him and lead him into a group of a bunch of kids he had never met, or didn't know. Which is not gonna work with somebody with autism, and say, "Here you are," and most of those kids were in there for problems like you know, trying to burn the school down or something.

Axial coding is defined as a "set of procedures whereby data are put back together in new ways after open coding, by making connections between categories. This is done by utilizing a coding paradigm involving conditions, context, action/interactional strategies and consequences" (Strauss & Corbin, 1990, p. 96). Axial coding relates subcategories to a category. Subcategories specify the features of a category (phenomenon) by focusing on its conditions; its context; the action/interactional strategies by which the phenomenon is handled, managed, or carried out; and the consequences of those strategies (Strauss & Corbin, 1990, p. 97). An example of axial coding is relating the subcategories of "Constant Worry" and "Constant Vigilance" to the category of "Mothers' Care."

Selective coding is defined as "the process of selecting the core category, systematically relating it to other categories, validating those relationships, and filling in categories that need further refinement and development" (Strauss & Corbin, 1990, p. 116). Selective coding is the final integration of the categories to form a grounded theory. Selective coding consists of five steps. These are (a) explicating the story line, (b) relating subsidiary categories around the core category (central phenomenon) by means of the paradigm (conditions, context, strategies, consequences), (c) relating categories at the dimensional level (location of the characteristics or attributes of a category on a continuum), (d) validating those relationships against data, and (e) filling in categories that may need further refinement and/or development. These steps do not necessarily follow a linear sequence nor are they distinct in actual practice, as one moves back and forth between those steps in the analytic process (Strauss & Corbin, 1990, p. 118).

Theoretical Sampling

Strauss and Corbin (1990) define theoretical sampling as "sampling on the basis of concepts that have proven theoretical relevance to the evolving theory" (p. 176). "Proven theoretical relevance" refers to those concepts indicated as significant because (a) they are "repeatedly present" or "notably absent" during the comparison of incidents, and (b) these incidents are determined to be relevant to categories through the process of coding (Strauss & Corbin, 1990, p. 177). According to Strauss and Corbin, all grounded theory procedures are designed to identify, develop, and relate concepts.

Strauss and Corbin (1990) explain the focus on sampling incidents:

> Our interest is in gathering data about what persons do or don't do in terms of action/interaction; the range of conditions that give rise to that action/interaction and its variations; how conditions change or stay the same over time and with what impact; also the consequences of either actual or failed action/interaction or of strategies never acted on. (p. 177)

Theoretical sampling determines the focus of the simultaneous processes of data collection and analysis. Because questions and comparisons that evolve during analysis guide theoretical sampling, initial interview questions and areas of observations are considered beginning guidelines only. According to Strauss and Corbin (1990), "the general rule in grounded theory research is to sample until theoretical saturation of each category is reached" (p. 188). Theoretical sampling continues until:

> (1) no new or relevant data seem to emerge regarding a category; (2) the category development is dense, insofar as all the paradigm elements are accounted for, along with variation and process; (3) the relationships between categories are well established and validated. (p. 188)

Quality Assurance

Qualitative researchers are concerned with making certain there is a close fit between the research data, results, and analysis. Qualitative researchers are more concerned with credibility than reliability and replicability, the latter being major concerns of quantitative researchers.

Two strategies to assure the accuracy of the data used in this study focused on auditability and credibility. Auditability refers to the ability of an independent researcher to follow the trail from data gathering to the theory with ease, with similar findings. In this study, care was taken to document the movement from the research questions to the findings and theory. In addition, the research committee served as consultants throughout the process, and decision points were reviewed regularly.

Credibility refers to the ability of the analysis and theory to reflect what is. In addition to the ongoing evaluation of the research committee, the findings were provided to research participants, and their evaluation of how closely the results fit their experience was incorporated.

CHAPTER 4

Results and Analysis

The purpose of this study was to develop a grounded theory of how mothers manage the care of children and adolescents with mental disorders, and their perspective about how their management of care has been labeled "overinvolved" by mental health professionals. This study addressed the following questions:

1. What factors do mothers consider when making decisions regarding the care of their child or adolescent with a mental disorder?

2. How do mothers describe the situations in which they were labeled "overinvolved" and what that experience was like for them?

3. What do mothers describe as the impact of being labeled "overinvolved" on their relationships with mental health professionals?

4. What do mothers describe as consequences of being labeled "overinvolved" on their parenting behavior?

This chapter reports findings from interviews with mothers about their experiences while caring for a child with a mental disorder. Two central phenomena, or two core categories, emerged during data analysis. The first phenomenon or core category was the impact of behaviors related to the child's mental disorder on mothers' strategies used to parent and care for their children. The second phenomenon or core category was the relationships between mothers and mental health professionals and between mothers and school personnel. For purposes of data presentation, the mothers participating in this study were given pseudonyms: Lauryn, Catherine, Rose, Beckett, Delores, Marianne, Linda, and Rachel.

Impact of Child Behavior on Mothers' Strategies

Child's Diagnosis and Behavior

Over the course of their involvement with mental health services, several of these children had been diagnosed with different psychiatric disorders, or were believed by mental health professionals not to have any problems at all. Despite this diagnostic confusion, and irrespective of the child's diagnosis, mothers focused on the child's behaviors that were dangerous; either to the child, or to others, or towards the destruction of property.

Diagnosis of the child's mental disorder. Mothers were asked about the diagnoses of their child's mental disorder. Recall that, of their current diagnoses at the time of these interviews, four of the children were diagnosed with bipolar disorder, one child had major depressive disorder, two children were diagnosed with autistic disorder, and one child had attention-deficit/hyperactivity disorder. It must be noted that, over the years, several of these children had been diagnosed with different psychiatric disorders, or were believed by mental health professionals not to have any problems at all. As Delores stated about her son, who was officially diagnosed with autistic disorder at age thirteen after spending eight years seeking help and direction from the medical and mental health profession, " . . . I came away with basically the impression that I was exaggerating, I was making up his symptoms, that he was a pretty normal kid, he really didn't have any problems that bothered him." Delores concluded that medical and mental health professionals were skeptical of her reports about her son's bizarre behaviors because he didn't exhibit these behaviors during the office visit:

> They didn't believe me when he was younger. I would tell them about all this stuff, and they didn't believe me because they didn't see it happen right in front of their face, or right at the time that they were with him.

The enormous frustration that some mothers may experience with the imprecision of the diagnostic process is conveyed by Delores of her now 20 year old son, who, in addition to his autistic disorder, is now suspected of having major depressive disorder:

> I probably in my lifetime have taken my son to over 50 different doctors for different reasons. I've gotten all kinds of diagnoses from, "he's perfectly fine," "he's

> totally normal," told, "he'll grow out of it," to now, you know. All I know is that he really needs some help.

Mothers' perspectives on child behavior. Despite the diagnostic confusion surrounding these children, and irrespective of the child's diagnosis, mothers typically were concerned about the child's extreme problematic behaviors that were impulsive, unpredictable, and unsafe, sometimes to the point of dangerous. These behaviors could be directed at oneself, towards others, or towards the destruction of property. For example, Rose's son, by 11 years of age, had set two fires that caused thousands of dollars in property damage. In another example, Lauryn talked about the beginning of her daughter's self-mutilation at age 13:

> And then she started all of a sudden when she got angry and one of the first times finding her, she's locked herself in the bathroom and she wouldn't open the door, and wouldn't open the door, and finally she did after she cut her toe with a razorblade and so it was just like the beginning of self-mutilation. She would find sharp things. Her forte was to scratch her arms when she was real upset.

Beckett described similar self-harming behaviors by her daughter who "used to go for the knife drawer and try to grab knives and threaten to kill herself and slit her wrists with the knives."

Some children displayed what mothers termed as "rages" that went far beyond what one would expect of a typical childhood temper tantrum. Rachel described that, at age 7, her daughter "would go into rages" that could last between "2 and 2 1/2 hours." During these rages, her 7-year-old daughter "would like tear apart her room, like when she tore wallpaper off the wall. And she would hit, hit me."

Beckett was instructed by a counselor to discipline her then 8-year-old daughter with "time-out" when she did not follow her parents' direction. It was the opinion of this counselor that the child had a "behavioral problem" and needed to be disciplined by "paying the consequences" for her oppositional behavior. If her daughter did not voluntarily comply with time-out, Beckett was instructed to make her complete her time-out by locking her in her bedroom for 8 to 10 minutes. Beckett described her daughter's response to this enforced "time-out":

> So when I put her into the time-out with the door shut and locked for 8 to 10 minutes, she would totally destroy the room. She had an amazing strength when she was in that frame of mind. It didn't work. She would take, she had metal bunk beds and she had a dresser and she would pull all the drawers and throw all the clothes around and then push the dresser down over, ripped the curtains down, the pictures off the walls, and then take the mattresses off the metal frame of the bunk beds and then flip the metal frame over. I was also always afraid that she would break the windows. Which she never did, thank goodness.

Despite the counselor's diagnosis of a "behavioral problem," Beckett stated, " . . . I knew then, in my heart, that this was not simply a behavior problem. There was something else going on with her: I had no idea what it was. But this is not healthy behavior for a person their age, even who's acting badly." Beckett also described her daughter's behavior after these incidents:

> Then she would just be drained . . . she would be hysterical and say things that I could not figure out what she was talking about and then she would end up curling up in a ball and falling asleep immediately after as if she had just been totally drained of every ounce of energy in her. And then she would wake up to, just be totally dumbfounded at what had happened and cry and say she was sorry and asked me to help her, "Please help me. You've got to help me," and pull on me.

Catherine talked about how, at age 15, her daughter's major depression finally became more than she could manage safely at home and still maintain a full-time job:

> She was becoming violent. She broke windows in the house and in the car. Punched holes in walls. Tried to, on the suicidal thing, she would try to get into the

> highway and be run over. She took medications that were poisonous, Tylenol. And she was becoming more and more depressed.

The mothers of the two children with autistic disorder described how the cognitive and neurosensory deficits related to this disorder contributed to their children's destructive behavior. Because Marianne's daughter has difficulty with verbal expression and understanding "a lot of things, her reaction usually is aggression. Biting me, hitting me, throwing furniture. I mean, we have broken doors, broken furniture, ripped clothing; 'cause she tends to chew on clothes, she rips things."

Delores described her son's repetitive patterns of behavior. The "obsessive-compulsive things he would do" could last for as long as 6 months until a different repetitive pattern of behavior developed in relation to his autistic disorder:

> He'd touch every car in the parking lot that had an alarm on it, you know, one of those talking alarms, he'd just go up and down the parking lot, touching cars, sitting on them and listening to them. And he might stay at one car for a long time, touching it over and over again. All he wanted to do was hear the alarms over and over. So, that was, again he had these like compulsions like pulling windshield wipers off the car. When he was younger, when he was really little, he would do the windshield wiper thing for a long, long time and then he got to, if you didn't keep your eye on him constantly, he'd want to run over and jump up on somebody's car and try to make the windshield wipers move. And then he learned that he could pull the windshield wiper off and you know, I was just constantly fighting this stuff. He would want to get in people's cars and want to shift gears to the point where he'd break the knobs off.

Several mothers reported calling the police during incidents when the child became extremely aggressive. Beckett stated, "several times I've contacted the police for different reasons. Her disappearing. And she has destroyed our property and by the time she got into her teen years I would call the police when she started to destroy property inside my house." Lauryn recalled "when the police came out" because her daughter was "totally out of control":

> . . . she was so bad that we had to call 911 'cause we were all holding her down and we couldn't do that all night. And we thought that they would just take her to JDH. Well no, they came, had to give her Inapsine, had to . . . handcuff her, put her in shackles, put a pillow case over her face because she was spittin' and just cursin', saying the vilest things, they were embarassing.

Rachel first called the police when her daugher, at 8 years old, tore down the curtains and tore everything in Rachel's bedroom. Rachel explained, "I had put her in my bedroom because I couldn't get her under control." Rachel recounted, "The police officer had to literally drag her out of the bed. She did not respond at all to the fact that this was an authority figure." The second time Rachel called the police, was when her daughter was 9 years old. Rachel found her daughter "with a rope around her neck, and she went into a total rage." When the police arrived, "two, three officers came in":

> There was a car of police and two sheriff cars. And they had looked like they thought maybe she was on drugs or something. And they took me into another room and when I came out, they had to, they had her handcuffed hand and foot because they could not control her, and the one officer had scratches down his arm with blood dripping.

Although mothers clearly recognized these behaviors to be self-endangering, aggressive, and destructive, mothers also interpreted these behaviors to be beyond the child's control. At the time when these incidents occurred, mothers did not always know that the behavior might represent symptoms of a mental disorder. These mothers knew that something was wrong with their child and that their behaviors were not typical of childhood or adolescent development.

Mothers' Strategies: Managing Child Behavior

Mothers developed strategies for caring for their child based on their perspective of how these behaviors adversely affected their child's life. Although the most extreme behaviors that mothers described of their child were impulsive, unpredictable, and unsafe, mothers also described problems that were related to their child's cognitive functioning that impaired their ability to understand concepts and social situations and, at the most basic level, to perform self-care activities such as hygiene, grooming, and dressing.

Mothers responded to the child's unsafe behaviors by trying to keep them safe. Not only were these behaviors at times self-endangering or very aggressive, they were usually unpredictable. The unpredictability and instability of the child's behaviors caused mothers to experience "constant worry" and to maintain "constant vigilance" over their child.

Constant worry, constant vigilance. Lauryn described the "constant worry" related to her daughter's unpredictable and dangerous behaviors:

> I'm sure people don't have to make sure that somebody was home for their, you know, she was probably at the height of it when she was 13, 14 and worried that their daughter might really hurt themself, or wondering when they'd come home, whether they have to go hunt their daughter down because we did that, several times. You know, we just go right where we could and start with her friends when she still had some at that time, and call and see if anyone could give us any tips, and at first we didn't get any. But the more these girls saw that Julie [really had some serious problems], the more they were willing to tell us where she was, as time went on. But I'm sure other parents didn't have to come home and figure out where they were, and go track them down, only to find that they were in bed with somebody, or strung out, or you know, just in somebody's house that was kind of, very questionable. I just remember doing that quite often and then just the worry, the constant worry, "Where is she? What is she doing? Is she gonna be safe? Or is

> she completely, you know, out of control, so that somebody could take complete advantage of her?"

Beckett's daughter would also take off from home when she was in a manic state of her bipolar disorder. During these periods of her daughter's illness, Beckett stated:

> We couldn't find her, and we didn't know where she was, where she lived, and all this other stuff, and what she was doing, and disappearing for long hours at a time, you know, you never really get out of her what she was doing, or where she was.

Mothers described the emotional and physical tolls of maintaining constant vigilance to safely care for one's child. Beckett described her extreme levels of frustration during the very unstable periods of her daughter's illness:

> I think when I describe things that Barrie would do, I was a very, you know, extremely frustrated, very, very much at my ropes and this was like when she was in junior high. I was at the end of my rope. You know, I would describe myself to her counselors and so on as "her psychiatrist", as "a mental health caretaker", "24 hour professional"; 24 hour, without a day off ever, never an ending shift of mental health care.

Delores understood the effects of her son's autistic disorder on his cognitive functioning. She explained, "The higher executive functions of the brain, like planning, organizing, sequencing, cause-and-effect type stuff seems to be lacking. There doesn't seem to be any fear of danger or awareness of it a lot of times." Her son's inability to understand cause-and-effect or the potential for danger in various situations described by Delores forced her to be constantly vigilant to keep her son safe:

> It was physically exhausting. It was very tiring. It was nerve-wracking in a sense, 'cause you knew, all you had to do was space out or not pay attention and you knew he'd run out in front of a car maybe, or be gone, or get lost, or something. You know, you had to keep track of him constantly.

Linda described the sudden changes in her daughter's behavior at about age 13. During this period, her daughter began to display extreme anger, oppositionality, impulsivity, irritability, hypersexuality, and was now no longer able to manage school. However, Linda was also able to recognize how she had to change her parenting of her daughter in response to these sudden changes in behavior to keep her daughter safe:

> Seventh grade, she'd been involved in activities in school and had friends. But once eighth grade came, we were dealing with really odd behavior . . . of this person that's angry, and impulsive, and she starts sneaking, and skipping school, and school's no longer an easy place for her. She was not happy there. She was breaking their rules. She was seeking out friends that were dangerous, or you know, inappropriate, or you know, the kids that you would not want her being with. The last days of eighth grade, they asked her not to even come to school. So now all of a sudden, the demands were we had to keep this child safe, but she was 12 years old, 13 years old and could get out of the house. And do things that were unsupervised. And you were still in the mode of, you know, you trust your child, "Oh, Mom, I'm going here," and you think that's where she's going. "Well, I'm with so-and-so," and so all of a sudden, parenting became very difficult, actually a job, you know, where you had to learn, which is a hard transition, to be very careful, very alert, hyper-alert to whatever she was doing. You had to actually, I would have to go into her room and search, really hard things that was [sic] not fun and didn't feel good.

Linda also described how much less freedom and how many more restrictions she experienced because of the increased level of supervision her daughter now required:

> With my other kids anyway, I could go on and do activities, and be out of the house, and not be concerned that she's not bringing people into the house and trashing the house, or whatever. I didn't have to be as hypervigilant, and so you

> kinda had to give up your life there for awhile and be there constantly, mentally, for what's gonna happen next.

Constant vigilance was not just about being hyper-alert to the behaviors and activities of the child. It included vigilance about the child's environment and taking measures to minimize the risks because of the child's impulsivity and unpredictability. Beckett described the changes she had to make at home when her daughter was focused on cutting her wrists with knives:

> . . . then I had to get all the knives and hide the knives. And there was the shaving thing and the knives and anything that's sharp, I'd hide. And that went on for years. And then after that I couldn't have those things in the home anywhere she could find them anyway.

Mothers' consideration of the safety of the environment also extended to persons and places outside the home where the child might visit. Catherine described her evaluation process when considering her daughter's depression:

> If she wants to go visit a friend, I think because of her tendency to be depressed and possibly suicidal, I have to be more cautious about whether the family that she's going to, or the friends individually, I have to kinda make sure that I can trust them as well as her, rather than if she were not depressed, then I would be more lenient . . . because I could trust her judgement and not have to worry about her safety, depending on the other circumstances the other family would bring in. So I have to consider each thing . . . , in making a decision, has to include how is the depression going to play into this setting.

Although many children are given their first bicycle sometime during their childhood, Delores explained why she did not buy a bicycle for her son:

> I wouldn't give him a bike. I wouldn't buy him a bike . . . it was just dangerous for him. He'd get on that thing and he would want to blare [sic] around the apartment complex and the parking lot, totally oblivious to cars and stuff. So that the next

> one, he actually rode off a 4 foot wall, it was the neighbor kid's bike. Breaking the frame in two bike pieces. So he didn't learn either. I mean he just did it over and over. I mean we went through several bikes . . . .

Although mothers responded to their child's unsafe behaviors by trying to keep them safe, they were not always successful. Underlying the constant worry and the need for constant vigilance was the recognition that they could not always prevent their child from running away or from self-harm. Mothers knew that they could not always keep their children safe from themselves or from the potential threat of others. The children described by these mothers had little, if any judgment; they were impulsive, and unpredictable, and thereby extremely vulnerable. It is perhaps this knowledge and awareness that generated the constant worry and constant vigilance described by these mothers surrounding the care of their children.

<u>Understanding special needs.</u> In addition to focusing on the child's unsafe behaviors, mothers responded to the impact of the mental disorder on the child's ability to function in school, or on his or her ability to understand concepts and social situations. At the most basic level, the mental disorder affected the child's ability to perform self-care activities such as hygiene, grooming, and dressing.

Beckett described the effects of her daughter's mental illness and how it "caused her to not be able to live an average life of a child her age."

> It interfered with her day to day routine of going to school and just having fun and being a kid, you know. And that's something that was, you know, debilitating. If you can't just get through a day, an average day, and that's where she was at.

Beckett and Delores both had their children placed on Individualized Educational Programs (IEPs) during elementary school. The Individuals with Disabilities Education Act of 1990 assures a public education to school-aged children with diagnosed learning disabilities. Under this act, public schools are required to design and implement an IEP tailored to each child's specific needs (National Institute of Mental Health, 1993).

Autism can severely limit children's ability to comprehend abstract information and to understand the subtleties of social interaction. Delores explained how "labor-intensive and time-consuming" it was "trying to explain emotions, trying to explain manners, feelings, abstract thoughts, concepts." Even at age 20, her son "still really hasn't gotten the idea of planning."

> I can say, "Let's plan something." But I can kinda see he still doesn't and I would have to somehow figure out a way to explain this concept to him, and then if that didn't work, I'd have to try to find another way and another way . . . it was like the word, "right/write." Write a letter, your right, turn right, conservative right, all the "rights/writes," you know. It was like that. So yeah, I think it took a lot more time for everything. Absolutely everything.

Rose understood that her son's attention deficit problems affected his ability to process information. She described how directions must be broken down in steps for him to be able to comprehend the information and follow through on an activity:

> You had to keep his time structured, you know, like at home, you know, keep him focused on his homework. Focused on his chores. You know you had to be with him, say, step by step, "You need to do this, first. And then you go into the second step, . . .". I mean you had to have it wrote [sic] down. And so he could read it, and be able to do it, and cross it off. Otherwise, if you gave it to him, like say, you need to feed the dog, you need to clean the room, you need to wash the dishes . . . it was like, "I can't," you know, he just couldn't comprehend all the information.

Delores also described her son's need for one-part instructions to get himself up and dressed for school:

> You know, he was like 9 years old before he could get up and get himself dressed for school. I was like, you know, "OK, it's time to get out of bed, it's time to go brush your teeth, it's time to take a shower, it's time to . . . you know, get your socks, get your socks on," the whole thing.

Mothers recognized the incongruence between the child's ability and what could be expected of a child at a certain age. With the examples of Rose and Delores whose sons required one-part instruction to follow through on an activity, it should be noted that in normal childhood development, a 2-year-old child can follow one-part instructions, and a 3-year-old child can follow two-part instructions (National Institute of Mental Health, 1993). Marianne described the difficulties that her 15-year-old daughter continues to have with basic self-care activities and its effects on how she cares for her daughter:

> When Anna was growing up, caring for Anna was probably typical. I mean I had to do the diapers, breastfeed her, you know, but throughout time, even though I still don't do diapers, I'm still bathing her, I'm still feeding her, and because she's not really independent, I mean I'm still having to, like I said before, you know, pick up her snot rags, or you know, other things like that, that you would think at 15 years of age, she should and could pick those things up. . . . And it's been approximately I think a year and a half since she had her teeth brushed even though she's in occupational therapy. Her therapist, myself, I mean other people have tried to keep that up. We've tried to teach Anna to do those things. I mean that's a perfect example, we've tried for years to teach Anna how to care for herself. And we're not sure why, we're not sure if she doesn't want to, or she truly lacks some understanding of why it's important, or that she should do it. Because her response usually is she doesn't want to, she doesn't care, why do I have to, which I don't see as being typical for 15.

Delores recalled having shared her observations with a counselor years ago, that her son "seems like such a much younger child." She specifically asked this counselor whether consequences for his behavior should "be age-appropriate, or should they be developmental-level appropriate." This counselor instructed her that "it was my job to basically bring him up to his age. I spent a lot of time trying to do that. . . . their advice and their opinions did change the way I interacted, treated him when he was younger."

Despite following the advice of these counselors, Delores found that her repeated efforts to "get him age-appropriate" were not effective at resolving her son's cognitive or behavioral difficulties.

When a child is young and has special needs, one hopes that the child will eventually catch up in areas of developmental delay with extra assistance or treatment. From mothers' examples of their child's difficulties, a relationship is described between the limitations of the child's abilities and the level of involvement in mothers' care. Yet for some children as they reach adolescence or young adulthood, it becomes more and more apparent to mothers when developmental delays must be considered and addressed as developmental disabilities. This may explain why some mothers feel they must continue their increased level of involvement in their child's care. Even as the child becomes older, this adolescent or young adult may not have the ability to execute the independence and autonomy normally expected during these life stages.

<u>Modifying care in response to changes in behavior.</u> Two mothers expressly commented on how their level of care changed when their daughters' behaviors became more stable and the child was better able to safely manage her life.

Lauryn stated, "I have backed way off this year. She is doing better so I can do this." She contrasted her daughter's current state at age 17 to the unstable behaviors that characterized her life at age 13:

> There's no more self-harm, that's gone, which is real nice. There's no more talk of suicide, there's no more even little reference of stuff, "I wish I were dead, I hate my life." There's less mood swings, and when there are, they're more like when she gets real low, she's kind of mean and . . . bitchy. You know, she just gripes about everything and she's verbally nasty. She does a lot of swearing. Or, if she's real high and giggly, but not to where she's, either way, it's not to where she's out of control. It's just to where it's kind of annoying. And she can look back and say, "I can't believe I used to do," this or that. . . . All along she has, just kept basically a

> diary, a journal, and her pictures, and she's kept them all together, and . . . every few months she'll go through her big box of stuff and she'll remember. And she, just afterwards, is when she'll come out and say, "I can't believe I used to feel that way," even reading her journal. So, it's really, makes me feel good to see that she doesn't think in that same hopeless attitude she had. It was awful. And she cares now. She cares, she has more respect for her body. That was that period of time, where you just don't know, she slept with anyone and everyone. You know she's been tested for AIDS, which thankfully was negative, but you know, she really needs a follow-up check, but it was just bizarre how she would just do all these impulsive, self-detrimental behaviors. It was real hard to understand.

Linda reflected on the change in her level of involvement in caring for her daughter once she became more stable at age 18:

> I think it's amazing. When you talk about "overinvolvement," or a parent that may appear to have given up their life, I think it's amazing once Mary was of an older age, had been through a lot of therapy, and her last treatment at 18, to come out of that. Well, even at 16, when she re-attached to us, but at 18 particularly, her looking at her life, and being, now needing to take care of her life, how amazing it is for a person that was labeled . . . "overinvolved," how easily I could give that up. How easily I could change the relationship to friends, to advocate, where she could come to me and say, "This, I want you to be involved with," and otherwise, having no desire to interfere, to get into her things, to look at what she was doing in her life, once she was behaving appropriately and safely. I felt at the time he was labeling my personality, that somehow I had a sickness, and to come through it, and suddenly say, "Oh, my goodness! I have no desire to be controlling, overinvolved in my child's life if it's safe, and . . . at 18, . . . to be able to say to her, 'Now you're legally responsible for yourself, you've been through a lot of things where you've had a break because you're a juvenile. Now you go into the adult

> system if you don't take care of business.'" And for her to be serious about that and change our relationship. . . . And I see that in other parents too, that I've dealt with, and talked with in the same circumstances. When you're in the crisis, when you're it, and you want this child to survive, and you're looking at all avenues, I guess you do become overinvolved. But what are you gonna do?

For Lauryn and Linda, there was no personal need or investment to be so involved in the care of their child. Mothers' level of involvement in their child's care was related to the specific needs of their child at the time. When the child was finally able to care about the quality of her life, and when the child was better able to manage her life safely, then mothers could be less involved and feel less responsibility to ensure the safety and well-being of their child.

Summary

Factors that mothers considered when making decisions regarding the care of their child included the child's safety and the child's special needs. Mothers were focused on keeping their child safe and finding ways to help their child manage day-to-day life.

Mothers focused on the need to keep their child safe because the child's behaviors were dangerous, either to the child or to others. During unstable periods of the mental disorder when the child was at high risk for danger to self or others, mothers believed that their child must be constantly supervised by having someone physically close by at all times to monitor the child and intervene if necessary to protect the child or others. This vigilance also extended to physically adapting the home to be a safer environment. Items in the home that could be potentially dangerous to the child, such as sharp objects like knives or scissors, were hidden or locked up so the child was unable to access these items. When assessing the safety of the environment, mothers also had to consider the people and the places that the child might visit.

Mothers believed that their child required a high level of structure and supervision to be safe. If the necessary supervision to care for the child in the home became more than what mothers or families could provide, or vigilance could not be maintained at the level that the child or others could be safe, mothers made the decision to place the child in a secure facility such as a psychiatric inpatient unit, residential treatment center, or juvenile detention center.

Mothers also focused on finding ways to help their child manage day-to-day life. The mental disorder could affect the child's cognitive functioning that impaired their ability to function in school, understand concepts and social situations and, at the most basic level, to perform self-care activities such as hygiene, grooming, and dressing. For children with diagnosed learning disabilities, mothers might place their child on Individualized Educational Programs (IEPs) which are designed to meet each child's specific learning needs.

Certain mental disorders, such as autism, can severely limit children's ability to comprehend abstract information or understand the subtleties of social interaction. Mothers could spend a great deal of time with their child trying to explain emotions, abstract thoughts, concepts, and the purpose of manners.

Due to the mental disorder, there may be an incongruence between the child's ability and what can normally be expected of a child at a certain age. Mothers may be advised by child specialists that they must try to bring their child up to the child's age-level of development. Despite mothers' attempts, they may find themselves unsuccessful and eventually discover that they must work with the child at the developmental level that the child is functioning. A 9-year-old child may require one-part instructions, typical of a 2-year-old child, from the mother every morning to dress himself to get ready for school. Mothers provided that level of structure and supervision needed by the child to meet the demands of day-to-day life.

Relationships: Mothers and Mental Health Professionals and Mothers and School Personnel

Mothers were questioned specifically about their experiences with the mental health professionals involved in their child's care. However, when describing how they had to care for their child with a mental disorder, 3 of the 8 mothers also talked about the difficulties that their child had in school in relation to the child's mental disorder, and how they addressed these difficulties with school personnel.

Mothers' Relationships with Mental Health Professionals

Mothers were questioned specifically about situations in which they were labeled "overinvolved" by mental health professionals. Conflict and disagreement characterized these particular relationships and were present in all the situations described. Disagreement between the mother and the mental health professional focused on how mothers responded to the child during unstable periods of the child's illness, or the child's treatment. Being labeled "overinvolved" evoked a variety of feelings as described by these mothers, such as feeling hurt, angry, frustrated, and criticized on how they parented and cared for their child. Being labeled "overinvolved" affected mothers' ability to trust those mental health professionals who had labeled them and future mental health professionals whom they later encountered in their child's treatment.

Though not questioned specifically about this issue, several mothers also described positive relationships with mental health professionals. These mental health professionals were characterized as being able to: listen to the mother; validate the mother's concerns; recognize the mother's need for support; and to effectively treat the child's problems.

Negative interactions: Mothers labeled "overinvolved". Mothers described their reactions to being labeled "overinvolved" by mental health professionals. Their reactions included feeling blamed, excluded, afraid, hurt, angry, frustrated, scapegoated, upset, devastated, and feeling self-doubt regarding their competency as parents. After their experience of being labeled "overinvolved," mothers felt distrustful of those mental health professionals who had labeled them and future mental health professionals who would later work with their children.

Lauryn questioned whether she had been wrong to have been so focused on her daughter and her unsafe behaviors, which the counselor conveyed had contributed to the escalation of her daughter's problems:

> It made it difficult because I, it just made you feel like gosh, I must have done, maybe I didn't handle it right in the very beginning, you know, maybe I was too focused on her, maybe, you know?

Two to three weeks after her daughter had been placed in a group home, Catherine was informed by her daughter's counselor that "it was time for Joy to grow up and it was time for me to get a life of my own." Catherine thought about the counselor's advice and considered that perhaps she did need to do more on developing her personal life. However, that she was viewed as being "overinvolved" with her daughter made Catherine feel as if she might be excluded from the treatment process. Her concern that she might be excluded made her fearful as to how she would manage the relationship with the mental health professional to continue to be part of the treatment process. The comments of the counselor gave her the impression that she would not be included in her daughter's treatment, despite whatever knowledge she might have from living with and caring for her child over the last 15 years:

> You know, I said OK, maybe that's true, let me think about it. That's what I said to myself. And I did think about it. And I did sign up for square dance lessons and kind of looked at, because I do put a lot of my time into my children because they have needs that take a lot of time. So I did try that. But at the time, I felt like she was just saying, "You, mother, get out of my territory and let me take care of this kid that I'm supposed to take care of." It wasn't, "Hey, you've spent 15 years of daily experience, what could you tell us that we could make use of?" There was no respect that maybe I had a contribution that could be helpful in her care. It was just

> a sense of, it's time for you to get a life and just, you know, move on down the road and stay out of our territory.

Catherine described her feelings about having to manage her relationship with her daughter's counselor:

> For me, it was a very fear-like, fear-driven relationship without control. Because I'm trying to meet her demands of getting a life, 'cause that's what she told me to do, so I have this list of what I'm doing for getting a life. But at the same time, I'm trying to see how I can influence this person who has control of my child. So you're trying to figure them out, you're trying to figure out how you're going to be satisfactory to them so they will continue to include you with your child. Otherwise, they're like shutting you out. You're overinvolved, you know, we don't want you, you go away.

Rose tried to give information about her son's history of ADHD and repeatedly tried to get information from her son's psychiatrist about diagnosis and treatment when her son was hospitalized. These behaviors were viewed as "overinvolvement" and Rose was excluded from the treatment process. After being labeled "overinvolved" by the psychiatrist, Rose described feeling "very hurt because of the fact that if I called, or when I went to see Mike, he refused to have anything to do with me." Beckett recalled that she felt "very, very hurt, and frustrated, and angry" about being negatively labeled especially after years of dealing with her daughter's unpredictable, impulsive, self-endangering behaviors.

Delores stated, "I'm just tired of being scapegoated." Her son's counselor was unwilling to periodically check up on him because of his adamant belief that her son has more capabilities than Delores knows he has because of her knowledge over the years of his limitations due to his autistic disorder. From the numerous times when she has had to monitor whether her son's counselor is maintaining any contact with her son, she described an incident where this counselor was "screaming at me about me forcing him because I have to constantly be intruding on my son's life one way or another." Delores described her frustration at her lack of success over the years to obtain adequate services for her son:

> It's a frustrating feeling 'cause you realize that things aren't falling into place like they should be, but you can't really figure out why you can't get any kind of results, or any kind of forward progress, I guess. And you think there's just something I'm as a mother not doing, somehow I'm not communicating with these experts, these professionals. I've come to really realize that it's more than just indifference or ignorance, it's almost convenient I think just to say, "It's mom and I don't have to bother with it."

Marianne described her frustration and anger because of her experience with the school and mental health system. She found the consistent focus on a family system and socioeconomic perspective in understanding her daughter's difficulties was detrimental to her daughter:

> I try to be diplomatic, I try to be honest, I try to be informative, but somehow Anna's story is just so negative, it's hard not to have it come out to be the equation, that you know, "Wow, I wonder what's wrong with the mother, she must be overinvolved," like it's a dirty word. It's not a child-focused system, I don't believe, certainly not in Anna's case. It's sort of like taking their eyes off of Anna and looking at where she came from, her mother, her family, her economic standing in the community, or that she didn't finish school, and then condemning her to a life with no services. A future with no hope. When the focus should be on her. It should be on any child. So, I mean that's part of what I was telling you that I get so frustrated and angry.

Marianne further described how she took her frustration and anger, at this negative interpretation of her overinvolvement with her daughter, and directed it into action as an advocate for autistic children and their families:

> Previous to this whole experience, I didn't think "overinvolved" was a bad word. But certainly in Anna's case and I've heard other families' stories, I mean they make "overinvolved" truly sound like a dirty word, which makes me mad. And I personally chose to take that word and turn it outward, if you will. I mean I know there's a lot of families that I work with and rightly so, and understandably so, they get depressed, marriages suffer, other kids in the family suffer . . . and I'm not saying I don't have . . . periods where I do get down, but because I'm on my own, raising two children, I really can't afford that luxury, and so what it's done is it's sort of become kind of my battle cry. . . . it just made me so mad, it just sort of spurred me more into action, and so, it became a springboard and a commitment that I made to Anna, to other kids, to be more informed, to be more knowledgeable, and fight for change. So I think that the people that called me that, and still call me that meant it for "bad," and I'm just choosing to do it for "good."

Linda was hurt and very affected by being labeled "overinvolved" by her daughter's therapist because she felt it to be "a criticism of my parenting, a criticism of how I was dealing with these extreme circumstances." Linda further added, "I felt at the time, he was labeling my personality, that somehow I had a sickness." Even though Linda could not conceive how she could have been less involved with her daughter during this period when she was engaged in self-endangering behaviors, Linda would now question herself on this. Linda recalled a situation where she distanced herself from her daughter because she had been labeled an "overinvolved" mother and how her lack of involvement in this situation proved to be to her daughter's detriment:

> And I think some things happened with Mary, there was a court case that she was involved in, . . . it was when she was 16. . . . But I said, "You take care of it." I'll let this child take care of this. I didn't get involved in getting her a good lawyer and everything. And she was convicted of something that she really, there was nothing she did do, . . . she got convicted and on her driving record something that she

> didn't do. Came back later, took pictures, later her [sic] and I went out, tried to do an appeal, you can't do that in court, but we went out, took pictures, and proved that the circumstances could not have happened the way she was accused. But it was too late, and that was part of, I think in the back of my head from then on, I always stepped back a little bit. And wasn't always there for her because in the back of my head, "Am I overinvolved? Am I too much for her?" And I think some of that may have happened as a result, just that label. If he could have just, you know, known in his mind, you know, this person is overinvolved, or needs an outlet, or whatever, or needs help. Well, guide me in that direction, but just to put that label on me? Just to lay that in my lap was very, very difficult. And did affect me for a long time emotionally, because he just didn't know, how can you be any less? The word, the concept, what are you gonna do with that? I think was hurtful.

Rachel stated that she had been labeled "overinvolved" by mental health professionals in "numerous situations," and chose to describe the most recent situation in which this had happened with her 17-year-old daughter. Her daughter had been hospitalized and was in the intensive care unit following "a very serious suicide attempt" which she had committed on the due date of her baby who was born prematurely and died shortly after his birth. After her daughter was medically stable, Rachel wanted her daughter to be transferred to an inpatient psychiatric unit of a hospital that was known to have good transition services as she had experienced problems before with the transition process in her daughter's previous hospitalizations. Rachel had mentioned to the therapist, "If possible, I would like to see her transferred into Hospital A."

> The therapist had made all these phone calls and she came back down and she said, "She's not going to Hospital A, she's going to Hospital B." Well, "Why not Hospital A?" And the therapist says, "Well frankly, if you're going for cosmetic surgery, that's the place to go, but I won't recommend it and I'm not going to send her there." So I was just too tired to fight. She goes to Hospital B.

> Well then the next question was how was she going to get there. The doctor had said that she would be transferred via ambulance. She was still in intensive care. This therapist decided that she didn't think that Oregon Health Plan would pay for her to be transferred by ambulance and therefore didn't think she needed to be, so she called Transport Services, and I said, "Well what kind of transport is this? Are there going to be two men in white uniforms showing up carrying my daughter away in a paddy wagon. What is this?" This therapist says, "Well I don't know." And I said, "Well can you find out? She says, "I don't have enough time," she had a group meeting she had to go to. And so I said, "But I want to know how my daughter is getting there?" And she wouldn't answer my question, she left. So we're sitting there for several hours waiting for this transport to show up. And I had told the doctor in the intensive care unit that if, you know, two men had showed up, or if it at all was something that I was uncomfortable with, she wasn't either going or I was going with [her].

Rachel ended up accompanying her daughter when two men from Transport Services arrived to transfer her daughter to Hospital B. Rachel explained her two concerns about this situation:

> One, I didn't think that was an appropriate way to take a child up that's been in intensive care. Two, I didn't think that liability-wise, that was a very wise thing for them to do, have two men with a teenage girl locked in a car, . . . it just wasn't right.

Rachel later called the therapist to inform her of her feelings of the way the situation had been handled. She described the therapist's negative view of her "overinvolvement" in her daughter's life:

> I called the therapist up and I say, "You know, I really don't appreciate the way that the transport was handled, and the way things were handled at the hospital. It was a very hard time for us and I was exhausted, I was worried. I think things

> could have been better." . . . And the therapist went off, she accused me of playing the social worker against her in the hospital and that I had no business saying, demanding--which I didn't demand, I just said, "I would like for her to go to Hospital A." And she accused me of demanding and that I wanted my own way, and said I "just needed to back off and let her do her job." That I was "too involved" and that I "didn't need to be that involved in my daughter's life."

Rachel described how upset and devastated she felt from the therapist's accusations:

> She had me on the phone for half an hour and I was so upset afterwards. . . . And she had me, I was literally shaking so bad, I could not stop shaking. . . . After all I'd been through, after losing my grandbaby, watching my daughter go through all that, almost losing my daughter, and have all this trauma, and then be accused of being, you know, "Back off and let me do my job," I was just devastated. Totally devastated.

Rachel also noted how previous incidents of being labeled "overinvolved" created self-doubt and questioning in her mind as to how she should deal with her daughter's behavior:

> It made me second-guess myself many times. And second-guessing myself probably was detrimental to Jessica because it . . . if anything, she needed consistency, and even if I was consistently overinvolved, it probably would have been better than to second-guess.

With the exception of Lauryn, mothers found that being labeled "overinvolved" affected their relationships with future mental health professionals who would later work with their children. After their initial negative experience or repeated negative experiences, mothers consistently described themselves as feeling distrustful of mental health professionals. They felt distrustful of mental health professionals because of their failure to understand mothers' perspectives of the situations in which they dealt with their children.

Rachel described her disillusionment: "Because you know, you want to trust professionals. Years ago, when I was a naive twit, I think back and I'm so angry with myself for listening and accepting in blind faith what people were saying to us." Being labeled "overinvolved" made them wonder how much mental health professionals really had to offer in the way of help to their child when such negative views of mothers were so readily embraced. Mothers now identified themselves as feeling "sensitive" or "ultra-sensitive" to how they and their management of care would be viewed as suspect to the child's problems. As Linda stated:

> I think that there was a sensitiveness there, you know. I didn't want them thinking in their minds that I was overinvolved, so I may not have been forthcoming with everything that was going on, or everything that I was involved in, in advocating for Mary. So I really, as I look back, . . . I wasn't as trusting after that.

Catherine also described how she consciously tried to appear "satisfactory" to her daughter's counselor after being labeled "overinvolved" so that the counselor would continue to include her in her daughter's treatment:

> Yes! It does [change your parenting behaviors]. Because like this example of the counselor in the first group home, then if I am interacting with Joy when this person's around, I will try to be as apparently uninvolved as possible, give the appearance of uninvolvement. I'll choose my words more carefully, I'll choose my actions more carefully to try to change that person's viewpoint.

Lauryn stated that her initial experience of being labeled "overinvolved" did not affect her relationships with other mental health professionals because it coincided with the development of another relationship with a mental health professional that was experienced positively.

<u>Negative interactions: Disagreement regarding mothers' responses to their child's behaviors.</u> Lauryn was concerned about her daughter's safety during the period when she was engaged in self-mutilation and running away from home. Her daughter's counselor,

who also met with the family for weekly family sessions, perceived Lauryn as contributing to her daughter's problems because she focused her attention on these behaviors. It was interpreted to Lauryn that her daughter may be behaving this way to get extra attention from her mother:

> But I would go away feeling like I must have done something wrong, sometime, because he said I was way too invested in what was going on with my daughter and that I was basically adding to the problem because I was way too focused on her. He was critical of how much attention I gave her compared to the other girls and which I couldn't quite, I still can't see how I could separate that when she was doing those kind of unsafe behaviors that just demanded attention. . . . he was real frank to say that I was overly involved with Julie, I gave her too much attention and that possibly that's why she kept escalating to do what she was doing 'cause she was basically . . . the message I got was that she was getting my attention in negative means.

Linda also was being seen in weekly family therapy by her daughter's individual therapist. Given her daughter's behaviors at that time, Linda could not see how it was possible that she be less involved in her daughter's care:

> . . . during this one therapy session, he said that I was . . . overinvolved. I was too controlling. And I was shocked! It really hurt me, I didn't say anything to him at the time. I accepted it, that I needed to get my own life, and that I was overinvolved. And I was more receiving this information, I wasn't responding and . . . it was like, "How can I respond to this information?" Well, it was a weekly therapy, so during that week, I started thinking about what he had just laid in my lap. And it was terrible! I had a child who was running to Eugene with a hippy commune, with no sexual protection, living there for two, three weeks, I had no idea where she is, until she gets back. But I'm searching, and you're calling police, and even at home, you know, your house is run differently because she has brought

> people into our house when we were out of town, and these people slept in our house, and drank in our house. And you know, I mean, there was intrusion, and it was laid on me, because I'm the parent to make sure she got the services she needed at school, and find the right medical care, and getting her into treatment, and then going through all the things you have to go through with treatment, having to drive to Eugene, and then to have somebody say I'm overinvolved. . . . how could I be anything less? How could I do anything less?

Negative interactions: Disagreement concerning the child's treatment. Disagreement between mothers and mental health professionals concerning the child's treatment were described when mothers wanted to actively particpate in their child's treatment, or if mothers believed that their child needed a specific treatment or more services than was being prescribed or recommended by the mental health professional.

Catherine and Rose described their experiences of being labeled "overinvolved" by mental health professionals because they had expected that they would continue to be involved in their child's care, despite their child requiring more intensive care, such as residential treatment or inpatient hospitalization, due to the acuity of the child's illness. Catherine described her experience with her daughter's first out-of-home placement. Catherine had always been actively involved in parenting her adopted daughter who was born with fetal alcohol effects. It was communicated to Catherine that now that her daughter was placed in this group home, Catherine no longer needed to be as involved in her daughter's care:

> . . . after Joy had a lot of difficulties at home . . . she went in to her first out-of-home placement in a group home. And I was under the impression that I was asking for help for my child who was 15 and still very bonded and afraid of going out into the world and lacked confidence in her ability to cope with the world on her own. She depended on me a great deal for that assistance. And there was a social worker type person, a counselor, and I've always been open to

> counseling. . . . I knew that I'd had difficulties with Joy, so I was very open to going to counseling to understand better, and to get her help, and move her, you know, keep her moving. And then, within a few, I would say maybe two to three weeks, this counselor was saying to me that it was time for Joy to grow up and it was time for me to get a life of my own. And I did not feel like she really understood the situation. And it was like, weird, it's like you're there holding somebody, so to speak, and then you're supposed to just let go of 'em and trust that, I don't know. I mean they didn't show me any signs that they were going to particularly step in to where I was at.

Rose was knowledgeable about her son's attention-deficity/hyperactivity disorder and what was helpful to her son given the effects of the disorder on his thinking and behavior. It was difficult for her to understand how this particular psychiatrist arrived at a diagnosis of schizophrenia. It was even more difficult to understand why this psychiatrist refused to discuss this issue with her. From his comments, the psychiatrist appears threatened by Rose's questions or opinions about her son's treatment:

> Dr. X. told me that Mike has schizophrenia. And I said, "Prove it," and he would never prove it. And as I was trying to work with the staff with him, he was saying, "You do not know what you're talking about and if you did, we don't need it." . . . He says, "Because of where you work at," he says, "you are too involved and you do not know what Mike's going through." And I said, "Yes, I do, because Mike has gone through this before, you know, with his severe ADHD problem and we need to keep it structured for him." And he says, "No, I do not want you to come and visit, I do not want you to have no [sic] associations with him."

Beckett and Delores reported being labeled "overinvolved" by mental health professionals because they disagreed with the treatment recommendations of the mental health professionals given their understanding and knowledge of their child. Beckett wanted her daughter to remain on medication. The family therapists wanted her daughter off her medication because they questioned the severity of her illness. Because Beckett wanted her daughter to remain on medication, they interpreted that Beckett wanted her daughter to be ill and needed her daughter to be ill for Beckett's own personal needs and fulfillment:

> (The therapy program is) a really, really intense family-oriented, supposedly no more than a year long day treatment center for kids with emotional and mental disorders and she had this counselor team, they believed that I was overinvolved. They recommended that Barrie stop taking medication and this made me upset because I expressed clearly in counseling that I feel like, you know, her taking a vacation from medication was a good idea, and that Barrie be encouraged to try some other medication. But they were telling Barrie, he told Barrie that she didn't have to take medication if she didn't want to, and that no one could make her take medication, and that he thought it was a good idea for her not to take any at all. And I said that was a dangerous thing to tell her at that point. And then they accused me of wanting Barrie to be ill, and wanting her to need me, that kind of thing, that you know, that I was overinvolved in it, that I needed to find something else in my life to preoccupy myself with, and so on, and so on, and so on. And it came to the point in a meeting where, a session where . . . I was still questioning him as to him telling my daughter that she didn't have to take any medication if she didn't want to, that he said, "Look, I want to see her, if she's as sick as you say she is, I want to see her kicking and screaming on the floor." And he said, "If we take this medication away, I'll get to see that." And you know, this was just so upsetting to me because I was the one who was going to have to take care of her while she was on no medication and I was really afraid of what she would do, and I was right. It was a horrible year. A horrible, horrible year.

Delores saw her son as someone with developmental disabilites who needed assistance to live independently in the community. Delores believed that case management services from the county mental health system would allow her son to continue to live independently. Because she provided much assistance to her son, he was able to do well. Delores did not feel she could decrease her level of involvement with her son until the county mental health system picked up that level of involvement by providing services. Their unwillingness to provide services appeared related to their view that he was fully capable of doing well on his own.

> . . . when he turned 19, I arranged, I got him an apartment. And I was calling (county mental health department) and saying, "Can we still get some services? Can we have somebody like a case manager, somebody who can check on him? So that, you know, he doesn't want his mommy checking on him all the time, he's trying to be really independent. And I don't want to have to be checking on him, I don't want to have to be constantly, you know, I want a life." And they're saying, "Well, he's doing just fine, he's doing just fine on his own." And I'm saying, "That's because I'm making sure that he has food. And I'm making sure that, I'm talking, and cueing, and reminding him, 'It's the first of the month, the rent's due. Have you budgeted, let's sit down and budget'." He won't budget by himself so you have to literally sit down and budget with him. "Have you paid your electric bill?" And I'm saying, "Can somebody else help with some of this? 'Cause I think he's a very disabled individual." . . . but so they're saying basically, at (county mental health department), said, "Just drop it, don't do anything, back out of this, well if he doesn't do OK, we'll step in and take care of him, we'll take over." And I say, "If I back out and I quit doing this stuff for him, he's gonna be living under a bridge, in no time. If I quit doing everything and he ends up basically in the criminal system, or homeless, then you guys will step in and do something. Until then, there's nothing. 'Cause you don't believe he needs any services." "Well he seems to be doing just fine." And well like, "That's because I'm the one who's taking him

> grocery shopping, I'm making and taking him to his dental." And he said, "Well you need to quit enabling him."

<u>Positive Interactions.</u> Several mothers reported relationships with mental health professionals that were experienced positively and found to be helpful. The descriptions of these mental health professionals indicated that they were able to listen to the mother, validate the mother, recognize that mothers needed support, and they were able to provide an effective treatment for the child.

The first psychiatrist who saw Lauryn's daughter was a general psychiatrist. Lauryn is a psychiatric-mental health professional who works with adolescents with severe mental illness. She suspected that her daughter might have manic-depression because of her symptom of extreme mood lability. The first psychiatrist diagnosed her daughter with major depressive disorder and only prescribed antidepressants, but her daughter continued to have problems. Lauryn described the situation where she suggested a medication trial of mood stabilizers for her child:

> I just suggested that I saw mood swings, could we try a mood stabilizer on her. He thought I was seeing too much into it, that that really wasn't necessary this time, he didn't see how that could help her, just the way he talked to me, kinda pooh-poohed [sic] my ideas and wouldn't discuss them. I think he had feelings about my input there.

Later, Lauryn was able to have her daughter seen by the new child psychiatrist who had just opened an office in town. She described this experience:

> We went to him and it was just like a whole, he, I swear he saved her life because he, in a 1 hour session, he said, "We're starting your daughter on Depakote, she's starting on Trazadone," she's getting all this, and he says, "Your daughter is a manic-depressive." He said, "There's no question about it." He said, "And I can't believe that we haven't started her on such-and-such." He was real surprised the other psychiatrist hadn't been more aggressive with the meds, but

> boy, within just a week, you know, you could see a big difference.

Lauryn later stated, "[We were] real glad we found that psychiatrist because things got better once we got the right person." Lauryn also talked positively about another therapist who had worked with the family when her daughter was previously in outpatient treatment. She sought the services of this former therapist for a second opinion after her daughter's current therapist in residential treatment labeled her "overinvolved," and believed she had contributed to her daughter's ongoing problems. Lauryn was able to share her thoughts and questions about how she had dealt with her daughter with this therapist:

> It made me start thinking, "Maybe I didn't handle things right." I started to look and see where there was something I could have done different. But she was real supportive, just matter-of-fact, you know, she would list things on the board, "Let's see Lauryn, you know, let's take a situation, let's see how you handled it," and kinda broke it down.

It appeared that Lauryn trusted this therapist enough that she was willing to find out if this therapist also viewed her as "overinvolved" in her care of her daughter:

> I kinda wanted to hear if they'd label me too. Really! I guess. 'Cause you know it hurts to hear them say that 'cause [you] just right away think, "My gosh, have I done something to contribute to all this? So even though it hurts, you do want to know.

Beckett was able to change her daughter's counselors who advised her daughter to stop taking medication. Beckett found the new counselor to be extremely helpful to her daughter because she focused her daughter on learning how to take care of herself:

> And then we got a new counselor that helped Barrie immensely. And her goal was to teach Barrie that if she felt like she needed help, she should get it, and ask for it. And to seek help, and not to, just remain helpless.

Beckett also found this new counselor to be extremely helpful to her because she focused Beckett on the importance that she take care of herself, too:

> This counselor says, "You need to learn how to take care of yourself . . . .You need to take care of yourself." That was always her goal, take care of yourself. When I would go to counseling, she'd say, "What have you done for yourself since I saw you last?" And that's something with parents like me that should be started from the very get-go, the beginning of all treatment, is, "What are you parents doing for yourselves? To take care of yourself so that you can see this through, to wherever it needs to go." Because their lives are so complicated, and stressful, and exhausting, and frustrating, that relaxation and stress-management thing should be the first thing.

After Rachel's phone call with the therapist who accused her of being "too involved" in her daughter's life that upset her to the point that she was "literally shaking so bad, I could not stop shaking," she had her husband take her to their family therapist so she could discuss the situation. Rachel stated, "And so I went to family therapy, so I gave her the scenario, and said, 'I need a reality check. Was I out of line here?'" After describing the situtation to the family therapist, she validated Rachel's actions and said, "You did everything that you should have done."

Lauryn and Rachel were extremely upset at being labeled "overinvolved" by the mental health professionals who were treating their children. Despite their upset and belief that they had behaved in a way that made sense to them given the situations of their children, one must note their courage and tremendous sense of responsibility to seek out another therapist who might also view them as "overinvolved" with their children. They were willing to look at themselves honestly with specific therapists with whom they had a trusted and established relationship.

Telling Beckett, "You need to take care of yourself," and following up the importance of this message by asking Beckett in each family session, "What have you done for yourself since I saw you last?" communicated the counselors's understanding and validation of Beckett in how she has had to care for her extremely ill daughter. By communicating her understanding and validation, she also acknowledged that Beckett must somehow find a way to take care of herself because of the mental, emotional, and physical exhaustion of caring for a child with a mental illness.

Mothers' Relationships with School Personnel

Beckett, Delores, and Marianne spoke critically of the school system in addressing the special needs of their children due to the child's mental disorder. All three mothers had strikingly similar experiences with schools in terms of unwillingness to acknowledge and failure to accommodate their child's special needs.

Beckett's daughter had been diagnosed and treated for an anxiety disorder when she was in middle school. Although Beckett explained to her daughter's teacher that she had an anxiety disorder and its effects on her behavior, the teacher addressed her daughter's behavioral difficulties strictly as a disciplinary problem:

> At that point the teachers she had at that time in sixth grade were putting a lot of pressure on her, that there was nothing wrong with her. And at one point she had not completed an assignment of some kind and they took her and put her in a time-out room. It was a little cubicle with no windows. And they put her in there and told her she couldn't come out until she had finished this project. And I had explained to this teacher that Barrie had an anxiety disorder. So you can pretty much expect what kind of state of mind Barrie was in that day when she came home. I mean she was absolutely psyched out, freaked from being in that little room. The pressure, the anxiety, she didn't do one thing in there, you know. That was the worst thing they could have done to try to get her to do something. She became suicidal, you know, during that time. Like about 10, 11.

Because of her daughter's continuing problems at school due to her anxiety disorder, Beckett wanted her daughter's IEP to be changed to "seriously emotionally disturbed" to better serve her daughter's needs. Beckett described the school's opposition to this requested change:

> I wanted to change her IEP to "seriously emotionally disturbed" is what it was called then. It's not called that now. And this teacher that she had in the sixth grade just thought I was the worst person in the world for doing that. She believed Barrie was normal. But that belief of Barrie being absolutely fine was causing Barrie a lot of stress and anxiety. And using some severe discipline tactics to try to get her to do things. And I remember that IEP meeting really well because she was there, and her special ed teacher, and Barrie and I, and she sat, this teacher, and just glared at me the whole time while we went through all the paperwork and everything, and was really disgusted that I was doing this. And so you know, after having a referral from a psychiatrist and Barrie being on medication and so many other things, I question and wonder how some people think they know more than people who are experts at it. It's not like we just ran out and did it in a few months. It was years of problems and it's not like it was a sudden decision or anything like that you know. Those kinds of things I think hindered Barrie's progress, obviously.

Repetitive patterns of behavior are only one symptom of autistic disorder, but this symptom can be extremely disruptive in the school setting. Delores' attempts to inform and prepare the teachers to anticipate this problem with her son were completely disregarded:

> And then I'd go in and I'd say that, like you know, his school counselors, at the beginning of the school year, I'd say, "There's a problem here with this kid, that's why I want to get all the teachers and I want to explain him before school starts." And they'd all go, "Yeah, yeah, yeah, we can handle him, yeah, no problem," and then I'd get calls at 9:30 at night from like, Mr. S., "What am I gonna do? He

> keeps doing this over, and over," you know. And to be basically dismissed or treated like I was completely the mental case.

Marianne first noticed her daughter's difficulties when she began kindergarten at age 6. When Marianne voiced concerns about her daughter, she described the school as unresponsive to these concerns. Because the school's position was that the daughter did not have problems or special needs, they attributed the problem to be with the mother. Marianne described the school's psychological and sociological explanations of her because she continued to seek services for her daughter:

> They thought maybe I was just an anxious mother. Maybe it had to do with issues surrounding the fact that we were basically at poverty level 'cause I was going to school at that time. Maybe I was distracted by my studies at school. Maybe it's because she didn't have a father. I mean, in the home, on the scene, whatever. Or that we didn't have any extended family.

Marianne's concerns about her daughter's problematic behaviors in school were validated by reports from children who told her that she was running away from school and hitting other children. When she presented this information to the school, the school denied that such problems were happening and continued to attribute the problem to be with Marianne:

> And even after I got Anna's diagnosis two years later, they were still saying it was a "home problem." They would say things like, "Well Marianne, if these problems exist such as you say, it must be a home problem because we don't have them here." And then when I would point out that kids have told me that Anna was running away, or that Anna hit them, the school just basically denied that, and then attacked me.

What is striking about all three examples is the apparent disregard by the school system in recognizing the child's special needs. These examples suggest that despite the existence of IEPs, the school system may resist providing special services to meet the specific needs of children regardless of any negative outcomes that may result for the child. The school system may continue to persist in the thinking that if any problems exist with the child, the source of the problems can be directly related to the mother.

Summary

Negative interactions between mothers and mental health professionals were characterized by conflict and disagreement. Situations in which mothers were labeled "overinvolved" focused on how mothers responded to the child during unstable periods of the child's illness, or the child's treatment.

Mothers were alarmed and very concerned about behaviors that endangered the safety of their child. However, their alarm, concern, and focus on these behaviors were interpreted by mental health professionals as contributing to the child's ongoing problems and limiting their child's personal growth. Mothers wanted to actively participate in and be informed of their child's treatment. When mothers offered unsolicited information such as their opinions, or information about the child's past history, such as their behaviors and special needs, the information was rejected or considered unimportant or considered unnecessary in mental health professionals' assessment, evaluation, and treatment of the child. This denial was despite mothers' years of knowledge from living with and caring for their child. Mothers were interpreted as needing their child to be "sick" to address their own personal inadequacies. Mothers were advised by mental health professionals as "needing to get a life" and be less controlling and involved in the lives of their child. Mothers were perplexed and confused by this view of them. They could not understand how it was possible to not be extremely worried about the impulsive, unpredictable, and dangerous behaviors, in addition to the child's specific cognitive limitations, that threated the safety and well-being of their child's life. They did not understand how it was possible to be less involved than they were because their child's life was in crisis.

Mothers experienced being labeled "overinvolved" negatively. Their reactions to this label included feeling blamed, excluded, afraid, hurt, angry, frustrated, scapegoated, upset, devastated, and feeling self-doubt regarding their competency as parents. From this experience, mothers described feeling distrustful of the mental health professionals who labeled them and future mental health professionals whom they later encountered in their child's treatment.

In contrast to mothers' negative interactions with mental health professionals, several mothers also described positive interactions. These positive interactions were characterized by the mental health professionals' ability to listen, validate, and support the mother, in addition to being able to provide an effective treatment for the child.

Negative interactions also characterized mothers' relationships with school personnel. Similar to the negative interactions with mental health professionals, conflict and disagreement were present in these relationships. Disagreement focused on how mothers or school personnel understood the child's special needs, or absence of special needs, and its relationship to providing special services to address those needs. Similar to the views of mental health professionals with whom mothers had negative interactions, school personnel tended to view mothers as the source of the child's problems.

CHAPTER 5

Discussion, Conclusions, and Recommendations

Developing the Grounded Theory

One purpose of this study was to develop a grounded theory of how mothers manage the care of children and adolescents with mental disorders, and their perspective about how their management of care has been labeled "overinvolved" by mental health professionals. Two central phenomena, or two core categories, emerged during data analysis. The first phenomenon or core category was the impact of behaviors related to the child's mental disorder on mothers' strategies used to parent and care for their children. The second phenomenon or core category was the relationships between mothers and mental health professionals and between mothers and school personnel. Strauss and Corbin (1990) discuss the constraints of developing two core categories and offer their recommendations when "two phenomena of interest strike the investigator as being equally important or of interest" (p. 121).

> It is essential, however, to make a choice between them in order to achieve the tight integration and dense development of categories required of a grounded theory. To fully develop two core categories, then to integrate the two, and write about them with clarity and precision is very difficult. This is so even for the experienced writer and researcher. (Essentially he or she would be developing and writing about two distinct but related theories.) The way to handle this problem is to choose one phenomenon, relate the other category to it as a subsidiary category, then write it as a single theory. Then, in another paper or monograph you can take up the second idea and do the same. (p. 122)

Subcategories specify the features of a category (phenomenon) by focusing on its conditions; its context; the action/interactional strategies by which the phenomenon is handled, managed, or carried out; and the consequences of those strategies (Strauss & Corbin, 1990, p. 97). The first phenomenon, the impact of behaviors related to the child's mental disorder on mothers' strategies used to parent and care for their children, was chosen as the core category for the theory, consistent with the purpose of the study. Mothers' perspective about how their management of care has been labeled "overinvolved" by mental health professionals, a subcategory of the second phenomenon, was also analyzed and integrated into the theory.

How Mothers Manage the Care of Children and Adolescents with a Mental Disorder

The Theory

The theory generated from this data is:

1. Mothers manage the care of their child by focusing on how the mental disorder interferes with the child's ability to function in day-to-day life. In particular, mothers focus on the complex interactions between behaviors that are dangerous to the child or others, and behaviors that indicate impairments in the child's cognitive functioning.

2. Mothers develop caring strategies for their child that attempt to keep them safe while working with the child at the level of his/her specific developmental delays.

3. There is a strong positive relationship between the limitations of the child's abilities or the child's specific needs and the level of involvement in mother's care. Mothers adapt their level of care to address their child's specific needs.

4. When there is conflict and disagreement in the relationships between the mother and mental health professionals, the mental health professionals label the mother "overinvolved" to the detriment of the care of the child.

The Story Line

The story line is the "conceptualization of a descriptive story about the central phenomenon of the study" (Strauss & Corbin, 1990, p. 119). The following is an explication of the story line of how mothers manage the care of children and adolescents with mental disorders.

Mothers manage the care of their child with a mental disorder by focusing on how the mental disorder interferes with the child's ability to function in day-to-day life. Irrespective of the child's diagnosis and despite the diagnostic confusion that may surround these children, mothers typically are alarmed and concerned about behaviors related to the child's mental disorder that are impulsive, unpredictable, self-endangering, aggressive, destructive, and beyond the child's control. Mothers develop strategies for caring for their child based on their perspective of how these behaviors adversely affect their child's life. In addition to their child's extreme behaviors that are impulsive, unpredictable, and unsafe, their child also may have impairments in cognitive functioning that limit the child's ability to understand concepts and social situations and, at the most basic level, to independently perform self-care activities such as hygiene, grooming, and dressing.

Mothers respond to the child's unsafe behaviors by trying to keep them safe. Mothers try to keep their child safe by maintaining "constant vigilance" over the child and over the potential risks in the child's environment. "Constant vigilance" means being hyper-alert about the behaviors and activities of their child and taking measures to minimize the risks in the environment, given their child's impulsivity and unpredictability. However, mothers know they cannot always keep their child safe or others safe, especially when the child's mental disorder is not well-controlled. Mothers have had the experience of their child running away, self-mutilating, attempting suicide, hitting them or others, and destroying property. Because mothers know they cannot always keep their child safe, there is "constant worry" about the child, especially during the unstable periods of the child's mental disorder.

For children whose mental disorder may affect their abilities to learn in school, mothers may place their child on Individualized Educational Programs (IEPs) so that accomodations can be made in the public school setting to meet their specific needs. Despite having the child on the IEP, mothers may experience resistance by the schools to meet the IEP, which can create an adversarial relationship between the mother and the school, as the mother finds she must advocate and continue to advocate for needed special services for her child.

Mothers recognize the incongruence between what their child can do and what could normally be expected of a child at a certain age. Depending on the type of mental disorder, the child may have difficulties with cognitive processing that can affect spoken and written language, coordination, self-control, or attention, such that the child's abilities are at the level of a child of a much younger age. Mothers find that to help their child meet the demands of day-to-day life, they must work with their child at the level of his or her specific developmental delays. The child's special needs may also require that mothers physically assist with the child's hygiene, grooming, and dressing.

There is a strong positive relationship between the limitations of the child's abilities or the child's specific needs and the level of involvement in mothers' care. Mothers adapt their level of care to meet their child's specific needs. Mothers seek mental health and school services to address their child's needs and to assist the child to better manage their young lives. Unfortunately, mothers may find that despite the existence of a mental health system and a public school system, services may be denied, or may be inadequate, or inappropiate. Services may be denied or lacking because the representatives of these service systems may view the child differently than the mother, believing that the child is much more capable and can function well, if only it were not for the interference of the mother. Their assessments and evaluations are always time-limited, whether an hour in an office, or several hours in a classroom, or for several weeks, or for several months, in an inpatient or residential setting. Despite mothers' experience and knowledge over the many years of living with and caring for their child, few, if any, questions or opinions are asked of the mother concerning the child. Because of this limited view of the child, they may view mothers' "overinvolvement" as the major problem in this mother-child relationship.

Conflict and disagreement characterize the relationships in which mothers are labeled "overinvolved" by mental health professionals. Conflict and disagreement between mothers and mental health professionals focus on how mothers respond to the child during unstable periods of the child's illness, or the child's treatment.

Mothers' alarm, concern, and focus on behaviors that endanger the safety of their child are often interpreted by mental health professionals as contributing to the child's ongoing problems and limiting the child's personal growth. Mothers who want to actively participate in and be informed of their child's treatment are also viewed as "overinvolved" in their relationship with their child. Unsolicited information, such as mothers' opinions or concerns, or mothers' information about the child's past history, such as their behaviors and special needs, often is rejected, or considered unimportant or unnecessary in mental health professionals' assessment, evaluation, and treatment of the child, despite mothers' years of knowledge from living with and caring for their child. Because of mothers' focus on the child's problematic behaviors, mothers may be interpreted as needing their child to be "sick" to address their own personal inadequacies. Viewed from this perspective, as a causative agent in their child's mental disorder, mothers are advised by mental health professionals "to get a life" and to be less controlling and involved in the lives of their child, so that the child does not have to "act out" against mothers' anxieties and their need for control. Such a perspective is completely confusing and perplexing to mothers. They view that the safety and well-being of their child's life is threatened by the child's impulsive, unpredictable, and dangerous behaviors. Mothers cannot understand how it is at all possible to be less involved in the care of their child because they view that their child's life is in crisis.

Given these circumstances of the child's behaviors and how mothers must develop strategies to manage these behaviors, the label of "overinvolvement" by mental health professionals is an extremely negative experience for mothers. They feel blamed, excluded, afraid, hurt, angry, frustrated, scapegoated, upset, and devastated, and experience considerable self-doubt regarding their competency as parents. From the initial trust when coming to this relationship in the hope that the mental health professional will help the child, and provide information and guidance for the mother to better care for and help the child, she experiences tremendous disillusionment. No concrete information or guidance is given to the mother on how to better help the child; she is merely labeled and criticized by the mental health professional. Mothers' sensitivity to this label can cause self-examination, self-doubt, and hesitancy that affect parenting of their child, causing them to be less involved or inconsistent in their child's care, to the detriment of the child.

Mothers develop strategies to address the mental health professionals' view of them as "overinvolved" because of their sensitivity to how they and their management of their child's care are now viewed as suspect to the child's problems. If fearful that the mental health professional may exclude the mother from the child's treatment, mothers may alter their interactions with the child in the presence of the mental health professional so that the mental health professional will perceive that the mother is "appropriately" involved with her child and not view her as critically. Mothers may try to align with the mental health professional through passive acceptance and agreement for the purpose of maintaining a satisfactory relationship with this person who is believed to have the knowledge, and resources, and therefore, the power to help her child. Mothers may be less forthcoming with the mental health professional about information regarding the child's activities or their strategies to care for their child in their attempt to convey a persona of a mother who can respond effectively to family therapeutic interventions, believing that as mothers, they must be viewed positively, in the hope that the mental health professional will try, and continue to help their child. However, at the point at which mothers begin to lose hope that this mental health professional may find an effective treatment, or provide appropriate services for her child, these "overinvolved" mothers attempt to remain hopeful that there may be another mental health professional who will be successful in helping her child. And when the mental health system is repeatedly unresponsive to their concerns for the needs of their child, mothers may take their frustration and anger and direct this energy into action as community advocates for children and their families in their fight to affect positive change in the system.

Mothers come to this relationship with the initial belief that their knowledge and experience of the child will be integrated to develop a comprehensive treatment for the child, only to find later that they and all of their opinions and concerns will be dismissed and disregarded. For mothers who have been labeled "overinvolved," a feeling of distrust now negatively colors the relationship. Relationships with future mental health professionals also are approached with apprehension and distrust due to this negative experience.

When their child's mental disorder is stabilized, or when their child is provided with an appropriate level of services such that the child is now more able to safely and responsibly manage his or her life, mothers then believe that their child is more capable, or has the necessary resources to meet the demands of day-to-day life. It is at this point that mothers believe they can be less involved and more removed from the care and management of their child's life.

Implications for Theory, Practice, and Research

The uncritical use of any theory can blind the clinician, theorist, or researcher to what is happening in a clinical situation. The remainder of this chapter will discuss theoretical implications, specifically how mental health professionals' rigid application of family therapy theory has contributed to the labeling of these mothers of children with mental disorders as "overinvolved;" clinical practice implications; and research implications.

Theoretical Implications

From the previous chapter, the following are the perspectives of the mental health professionals that earned mothers the label of "overinvolvement." In her relationship with her daughter, Lauryn was "way too invested," "way too focused," "overly involved," and "gave her too much attention," which, according to the therapist, was possibly why her daughter "kept escalating" her unsafe behaviors of self-mutilation, running away, and promiscuity. Linda was "overinvolved" and "too controlling" with her daughter who was also running away, inviting questionable people into their home, and drinking. Catherine was "very open to going to counseling to understand better and get her [daughter] help and move her, keep her moving" so that her daughter could eventually become stable in her functioning and return home, but "this counselor was saying to me that it was time for Joy to grow up and it was time for me to get a life of my own." Beckett had years of dealing with her daughter's anxiety, obsessive-compulsive behaviors, mood lability, and disrupted sleep patterns and knew from her daughter's experiences over the years that medication was necessary to manage her symptoms. Because Beckett believed that her daughter's mental illness could be stabilized with medication, she was "accused . . . of wanting Barrie to be ill, and wanting her to need me." Beckett was told that she was "overinvolved in it" and "needed to find something else in my life to preoccupy myself with." Delores was extremely knowledgeable of her son's limitations posed by his autistic disorder and recognized that he required a certain level of supervision and structure to live successfully as an "independent" young adult in the community. Delores tried to explain the level of case management services that her son needed by describing how she had to work with her son so that he could continue to live independently in the community. From her description of her activities to assist her son, she was described as "enabling" her son.

These examples suggest that the mental health professionals were operating from the theoretical perspective of family therapy to understand the symptoms of mental illness present in these children and to arrive at their interpretation of these mothers as "overinvolved." Wynne (1988) gives a definition of family therapy:

> Family therapy is a psychotherapeutic approach that focuses on altering interactions between a couple, within a nuclear family or extended family, or between a family and other interpersonal systems, with the goal of alleviating

> problems initially presented by individual family members, family subsystems, the family as a whole, or other referral sources. (p. 9)

Therefore, the goal of family therapy is to alter problematic family interactions. The focus of family therapy theories about the family is the examination of family interaction patterns that lead to individual, marital, and family dysfunction.

Doherty and Baptiste (1993) discuss fundamental assumptions of family therapy theories as it has addressed issues of mental health and family problems. The primary assumption is:

> Family relationships are a principal source of mental health and psychopathology for individuals. This is perhaps the founding assumption of family therapy. If one wants to understand symptomatic behavior in an individual, look first at family interactions. Although psychoanalytic theory rooted adult psychopathology in the child's early family experiences, family therapy theory also stresses the importance of current family interaction patterns in promoting and maintaining individuals' problems. (p. 511)

A second assumption is that, "family health requires a balance of connection and individuation" (p. 511), which is the balance between family solidarity and individual autonomy. Children raised in families with too much connectedness will have difficulty leaving home emotionally; children raised in families with too much separateness will have difficulty trusting others (p. 511). In both situations, "it is considered likely that some family members will show signs of psychosocial pathology" (p. 511).

A third assumption is that, "family flexibility is a core trait that prevents family dysfunction" (Doherty & Baptiste, 1983, p. 511). Families who demonstrate flexibility are "families who can shift their beliefs and interactional styles in the face of developmental change and environmental challenges" (p. 512). These families are most likely "to avoid relational problems and psychosocial pathology in family members" (p. 512).

A fourth assumption is that, "individuals' symptoms frequently have meaning within the family's interaction patterns or worldview" (p. 512). The symptoms of one family member are assumed to be related to what is occurring with other family members. A classic example is "the rebellious teenager whose actions serve to maintain the solidarity of the parents' marriage by inducing them to join forces as parents" (p. 512).

These mental health professionals appeared to operate from the theoretical perspective of family therapy. Within the context of the family, mothers' behaviors towards their children reflected inflexibility and too much connectedness. It may have been that these mental health professionals saw these mothers as interfering with their child's attempts to separate from them because of the mothers' own personal difficulties of facing the changes in their role and their identity, as their children struggled to become more independent and autonomous in keeping with their adolescent or young adult development. Their child's symptoms of mental illness were seen more as a reflection of the mothers' own personal inadequacies and resistance to allowing their child to grow up. The situations that Lauryn, Linda, and Beckett described of being labeled "overinvolved" occurred when their daughters were about age 13. Catherine's daughter was 15-years-old and Delores' son was 19-years-old.

However, by being so entrenched within a family therapy theory, these mental health professionals were unable to hear and understand the fear and concern of these mothers as it related directly to the unpredictability of their children's impulsive behaviors that put their safety and well-being at risk. It also appears that these mental health professionals were unable to consider that the symptoms and behaviors of the child might be viewed as a brain dysfunction, which is yet another and more recent theory in the understanding of mental disorders. These mental health professionals' ability to understand these mothers' experiences of caring for their mentally ill children appear to have been bounded by a particular theoretical orientation limiting their perspective to viewing these mothers as "overinvolved" while their children responded to their mothers' overinvolvement by being "out of control," or not taking control of young adulthood responsibilities, thereby "acting out" the dynamics of family dysfunction.

According to Doherty and Baptiste (1993), "family therapy theories emerged from efforts to understand and treat families of mentally ill children and adults" (p. 512), therefore, "the major problems addressed by the theories naturally have focused on what goes wrong with families" (p. 512). Theories that assume families are the cause of a child's difficulties influence what clinicians are able to see and hear as the families attempt to express their needs and concerns. Individual, group, and family therapy are traditional treatment modalities in mental health settings. Therefore, family therapy theories have been an established and accepted perspective within the field of mental health. They are included in all curricula of the various mental health disciplines, such as medicine, nursing, social work, and psychology.

However, from a historical perspective, one must acknowledge that theories reflect what is understood about a particular phenomenon at a certain period in time. Our understanding and current beliefs about a particular phenomenon are based on all that is known about that phenomenon, until further discovery of new knowledge. Discovery requires one to be open to new avenues of information and to possibilities previously unconsidered. Theories can provide guidance in the understanding of phenomena, but should not limit one from discovering other points of view. Therefore, theories should guide the clinical practice of all the mental health disciplines, and not rigidly blind clinicians to the possibilities of new perspectives from which we may understand our clients.

Clinical Practice Implications

Mental health professionals with whom mothers experienced positive relationships exhibited specific characteristics. These mental health professionals listened to mothers, validated their observations of the child, validated their decisions and efforts related to the care of the child, recognized that mothers needed support, and were able to provide an effective treatment for the child. These specific characteristics suggest that mothers found an empathic approach to be helpful when working with mental health professionals. These findings are consistent with Modrcin and Robison's (1991) work. They examined how professionals who provide services to families with children with emotional disorders "can establish a working relationship with these families by creating an empathic context for their work" (p. 282). Empathy is "a process of listening and perceiving in a certain way so as to grasp some aspect of the person's inner experience" (p. 282). They note:

> People need to feel understood and that their needs and desires are comprehended by an important person in their life. When professionals can communicate this level of understanding to families, an opportunity is created for a working relationship built on empathy and respect. (p. 282).

Modrcin and Robison (1991) suggest that the following issues must be considered for professionals to facilitate empathy and respect in a working relationship with families. A family does not anticipate the onset of a severe emotional, behavioral, or mental disorder in one of its children. This event is non-normative because it is unexpected and has not been anticipated as part of the developmental stages of the family life cycle. Normative events allow a family to anticipate change and adjust to new tasks and challenges presented in the transition to the next developmental stage. Recall how Lauryn, Catherine, and Linda could describe the sudden changes in their daughters' behaviors with the onset of symptoms that affected how they had to care for their daughters. Modrcin and Robison note that the onset of a mental disorder can create a "state of crisis" for parents and can disrupt "communication patterns, family roles, and living patterns for the family" (p. 284). Delores described how her decisions to manage the care of her son with autistic disorder led to an estrangement with her family:

> In my family, they thought he was a spoiled, rotten brat whose mother was just making excuses for him . . . who didn't hit him, didn't beat him enough. What he needed was a damn good beating, and get his butt spanked and he'd straighten out.

> It caused that kind of interaction, that kind of conversation going on and on to the point where I have nothing to do with any of my relatives. And I also had those kind of discussions with his father.

Children with mental disorders present a unique set of developmental challenges to which families must adapt and adjust. According to Modrcin and Robison (1991), the "cognitive and emotional development of a child with a serious emotional disorder does not follow predictable developmental stages" (p. 284). In addition, "increased caretaking needs of the child or adolescent will exceed developmentally expected demands" (p. 284). This is consistent with the findings of this study in which mothers believed that their child required a high level of structure and supervision to be safe and to meet the demands of day-to-day life. Modrcin and Robison also acknowledge the disruption of the family life cycle regarding the "stages of predictable parental roles" in which parents "anticipate an increased interaction and independence in their relationship with their children" (p. 284). The disruption of "predictable parental roles" is exemplified by Delores and Marianne as they must continue to provide a high level of involved care to a young adult son and to an adolescent daughter due to the effects of autistic disorder on their childrens' level of functioning.

Parents of children with mental disorders face long term support issues that extend and modify the parenting role beyond expected years. Because of the increased needs of the child due to the mental disorder, parents will have difficulty anticipating "when their roles will change, how to encourage normal separation activities and how to deal with emotional ties to their children" (p. 285). This is exemplified by Delores who desperately sought case management services with the county mental health department to assist her young adult son living in the community. As she stated of her son and of herself, "he doesn't want his mommy checking on him all the time, he's trying to be really independent. And I don't want to have to be checking on him, . . . I want a life." Delores wanted to be less focused on his care, recognized her son's need to be independent, and wanted the freedom to be able to pursue and develop her own life.

Families need a range of coping strategies and resources to manage the stress in their lives. According to Modrcin and Robison (1991), "self reliance and a belief that one can impact the environment in which the child resides appear to be important variables associated with family coping" (p. 287). Self-reliance as a variable in effective family coping is consistent with Beckett's experience in which her new counselor emphasized the importance that she must learn how to take care of herself. From this counselor, Beckett discovered:

> . . . that's something with parents like me that should be started from the very get-go, the beginning of all treatment is, "What are you parents doing for yourselves? To take care of yourself so that you can see this through, to wherever it needs to go." Because their lives are so complicated, and stressful, and exhausting, and frustrating, that relaxation and stress-management thing should be the first thing.

The "ability to impact the environment in which the child resides" may be experienced by parents if their child's IEP is effectively implemented in the school system. This may also be experienced if parents are allowed to be actively involved in their child's treatment and may enable them to more effectively cope with the stress of their child's illness.

If clinicians are genuinely interested in developing a working partnership with the parents of a child with a mental disorder for the purpose of helping the child and the family, this study suggests that it is extremely important to approach them from the perspective that they have much knowledge and information to share about their child from years of living with and caring for the child. With that perspective, clinicians must ask parents about their experiences and knowledge of their child, and listen and attend to what they believe are important points in the child's history. Clinicians must acknowledge the fact that only parents have had the opportunity to observe their child in multiple "real life" situations and can inform the clinician on how the child has responded under various conditions. A truly comprehensive assessment of the child requires such information that only parents can provide.

When listening to parents, one will quickly discover that caring for a child with a mental disorder is extremely stressful and that parents need support as well, in this demanding and frequently, heartbreaking endeavor. For some parents, it may feel to be at times an endless endeavor. To survive the crisis and the intermittent crises that may follow characteristic of the chronicity of mental illness, parents and families will benefit from the support of understanding and validation. Families have frequently found this support from family support groups because the members of these groups have shared similar experiences. If clinicians are also to be a source of this support and provide truly meaningful and helpful interventions, they must be able to openly listen and resonate to the loss, disappointment, and stress of the family's experience.

From a philosophical perspective, a recognition of the family's strengths and contributions reflects a family-centered model of service delivery (Allen & Petr, 1998). Allen & Petr describe this model:

> In contrast to child-centered or professional-centered approaches, the family-centered model of service delivery focuses intently on the crucial role of the family in the healthy development of children. The foundation of this approach is that positive developmental outcomes and overall family well-being are best achieved when the service system diligently supports the abilities of families to meet the needs of their children. (p. 4)

Allen and Petr (1998) acknowledged that controversy surrounds family-centered approaches. From child-centered professionals who have tended to focus primarily on the child, there are concerns that "an emphasis on the family may result in decisions that are not in the best interests of the individual child" (p. 5). A child-centered orientation has typically viewed the family "as the source of problems, an obstacle to the child's growth, or irrelevant to the intervention process" (p. 5). Another concern regarding family-centered approaches is that it reduces "the power and authority of professionals in the push to please and empower parents" (p. 5). For "those trained in the traditional medical model of professional behavior" (p. 11), in which clients are expected to be passive and compliant recipients of expertise and authority, this approach may be viewed as "threatening or irresponsible" (p. 11). Because families have resented and disputed this view of the family in child-centered approaches, it has been parents rather than professionals who have been the impetus for change toward a family-centered approach in service delivery.

Allen and Petr (1998) defined "family-centeredness":

> Family-centered service delivery, across disciplines and settings, recognizes the centrality of the family in the lives of individuals. It is guided by fully informed choices made by the family and focuses on the family's strengths and capabilities. (p. 9)

In contrast to a culture in which professionals have been trained to "use their expertise to control and direct interventions" (p. 11), a family-centered approach to practice "asks them to provide information, knowledge, and options to families, and then to respect decisions that the families make" (p. 11). Instead of focusing on deficits and "dysfunction" that frequently leads to criticism and blaming, a family-centered approach asks professionals also to identify and support the strengths and abilities of families.

The characteristics identified by mothers in which positive relationships were described with mental health professionals are consistent with a family-centered approach to practice. Adopting a family-centered approach when working with parents may facilitate more effective working partnerships between parents and professionals.

Research Implications

This study evolved from listening to mothers in a family support group. The major question of this study, how mothers are labeled "overinvolved" in their care of a child with a mental disorder, came from listening to mothers discuss how this had been experienced as a problem in their relationships with mental health professionals working with their child. The exploratory research design and the method of grounded theory proved to be useful for the purposes of this study. It allowed an empirically grounded theory to be generated about a phenomenon, the labeling of mothers as "overinvolved" in their care of a child with a mental disorder. The generation of this theory gave voice to these mothers about their experience of this phenomenon at the level of research.

This study examined only one perspective of the parent-professional relationship, focusing on mothers' experiences. Future research could explore the concerns of mental health professionals about mothers' or parents' care of children with mental disorders to gain understanding of how their concerns may influence their relationships with parents. Examining both perspectives of the parent-professional relationship may help researchers and clinicians to better understand the conflicts in this relationship and gain ideas on how possibly to address or resolve those conflicts for the purpose of improving our service delivery to families.

Summary

The purpose of this study was to develop a grounded theory of how mothers manage the care of children and adolescents with mental disorders, and their perspective about how their management of care has been labeled "overinvolved" by mental health professionals. Published research on parents' caregiving experiences of children with mental disorders has been focused on adult children with mental illness (Belcher, 1988; Bulgur, Wandersman, & Goldman, 1993; Chafetz & Barnes, 1989; Chesla, 1989, 1991; Cook, 1988; Eakes, 1995; Greenberg, 1995; Howard, 1994; Pickett, Cook, & Cohler, 1994; Ryan, 1993; Tuck, du Mont, Evans, & Shupe, 1997). In the only publication found to date on family caregiving of younger children, Weiss (1991) examined the stressors of parents caring for children with pervasive developmental disorders. Therefore, our knowledge of parents caregiving experiences, especially of younger children with mental disorders, has been limited.

Purposeful sampling was used to select participants for this study. Eight mothers were recruited from the Oregon Family Support Network who met criteria for participation in the study. Criteria for participation were mothers of biological or adoptive children between the ages of birth and 21 years who were diagnosed with a mental disorder classified in the DSM-IV (American Psychiatric Association, 1994). Only mothers who reported having been labeled "overinvolved" (or "overprotective") by a mental health professional on at least one occasion were included.

This study used an exploratory research design. The methods of grounded theory were used to investigate mothers' observations of their child's mental disorder and its impact on child behavior, and their understanding of their child's special needs related to the mental disorder, in order to develop a theoretical formulation of their decisions regarding the management of care of their child. Data collection consisted of one audiotape recorded, semi-structured interview with mothers at her home or at a quiet, convenient location of her choice.

Two core categories emerged during data analysis. The first core category was the impact of behaviors related to the child's mental disorder on mothers' strategies used to parent and care for their children. The second core category was the relationships between mothers and and mental health professionals and between mothers and school personnel.

Factors that mothers considered when making decisions regarding the care of their child included the child's safety and the child's special needs. Mothers focused on the need to keep their child safe because of the dangerousness of the child's behaviors, either to self, or others. Because the mental disorder could impair the child's cognitive functioning and development, mothers also focused on finding ways to help their child manage day-to-day life. Keeping their child safe and able to meet the demands of day-to-day life required a high level of structure and supervision that was determined by the child's level of functioning.

Negative interactions between mothers and mental health professionals were characterized by conflict and disagreement. Situations in which mothers were labeled "overinvolved" focused on how mothers responded to the child during unstable periods of the child's illness, or the child's treatment. The situations described by mothers in which they were labeled "overinvolved" suggest that mental health professionals were operating from the theoretical perspective of family therapy to understand the child's symptoms as a manifestation of family dysfunction, specifically mothers' "overinvolvement" as evident by mothers' intense focus on the child's unpredictable and dangerous behaviors.

Mothers experienced being labeled "overinvolved" negatively. Their reactions to this label included feeling blamed, excluded, afraid, hurt, angry, frustrated, scapegoated, upset, devastated, and feeling self-doubt regarding their competency as parents. From this experience, mothers described feeling distrustful of the mental health professionals who labeled them and future mental health professionals whom they later encountered in their child's treatment.

In contrast to mothers' negative interactions with mental health professionals, several mothers also described positive interactions. These positive interactions were characterized by the mental health professionals' ability to listen, validate, and support the mother, in addition to being able to provide an effective treatment for the child.

Negative interactions also characterized mothers' relationships with school personnel. Similar to the negative interactions with mental health professionals, conflict and disagreement were present in these relationships. Disagreement focused on how mothers or school personnel understood the child's special needs, or absence of special needs, and its relationship to providing special services to address those needs. Similar to the views of mental health professionals with whom mothers had negative interactions, school personnel tended to view mothers as the source of the child's problems.

Clinicians must be careful in their use of theory as it influences their practice. Theories that assume families are the cause of a child's difficulties influences what clinicians are able to see and hear as the families attempt to express their needs and concerns. Used appropriately, theories can guide clinical practice, but should not limit our ability to listen to other points of view that can facilitate our work with clients.

Approaching parents with empathy and respect can facilitate a working partnership between clinicians and parents. By creating an empathic context in their work, clinicians can offer the support of understanding and validation to parents. A family-centered approach to practice can guide clinicians to provide information and options to families, allowing families to make decisions based on informed choice, and respecting the decisions of the families. This approach to practice can also guide clinicians to identify and support the strengths and abilities of families, instead of focusing on dysfunction, a characteristic of traditional family perspectives.

This study examined only one perspective of the parent-professional relationship, focusing on mothers' experiences. Future research could explore the concerns of mental health professionals about mothers' or parents' care of children with mental disorders to gain understanding of how their concerns may influence their relationships with parents.

Postscript

Toward the end of her interview, Delores gave this metaphor to describe her struggle to obtain help for her son:

> I feel like there's a whole swimming pool full of kids there, they're all swimming, and everybody's saying, "Would you quit making so much noise about your child?" And I go, "But mine's drowning," you know, "mine's drowning."

For me, this metaphor clearly captured the essence of what these mothers revealed to me about their experiences in seeking help from the mental health care and the public school system. It is as if these systems are saying, "No one will know that he is drowning or that he even drowned, as long as you stay quiet about it."

What was striking for me about these stories was how mothers approached these systems for help with their child, only to find that the representatives of these systems were rigid and inflexible to the needs of the child and that mothers were criticized and ridiculed as they persisted in trying to find help in the form of effective services. These mothers did not comply by acquiescing to these systems representatives. Given that client/patient "compliance" to health care prescriptions is a goal, if not the goal for many clinicians, their lack of compliance very likely contributed to the many problems in the parent-mental health professional relationships described by these mothers.

In my clinical experiences of working with parents, I have found that "walking in their shoes," by truly listening to their stories and suspending theoretical bias, has been a most helpful and enlightening experience. I first discovered this during my opportunity to work in multi-family therapy groups at the Yale Psychiatric Institute. It was a weekly group to which there were two parts to the group. The first hour was spent with the parents explaining the recent events of the unit, and answering questions and addressing any concerns that they might have. It was clear that there were the Parents and there were the Professionals in this group.

The second part of the group included children, parents, and professionals. What was striking about this group was the clear boundary between the parents and professionals, and the children. There was this sense of unity between parents and professionals (the adults who cared for these children) that could always be felt in this second group when we presented to the children, but not always in the first group, which could sometimes feel conflicted and divisive. Afterward, there were refreshments for everyone. It was a time to socialize and not analyze. According to the unit chief, the multi-family groups were tremendously helpful in reducing complaints from parents, and I could see why. You really got to see each other from a different perspective because these groups gave us the time to be together (from 7 to 9:30 pm) and talk to each other. This is not to say that we didn't have our differences, or that we didn't observe psychopathology in the parents, or that they didn't observe incompetence in us. However, I think it gave us all, the parents and professionals, the opportunity to be on the same side and remain united, wanting the best for the children and being able to work out our differences for the best of the children.

"Walking in their shoes" was also felt in my interviews with these mothers. I should add that I also experienced this in my participation in the family support groups. I know that as a researcher, one must approach the research process with objectivity, but the stories told in these interviews were extremely personal, and I also heard their stories as just this person, as just this woman with many years of clinical experience. I have often thought that given their difficulties in raising a child with a mental disorder and all that the disorder brings, that this was probably never anticipated, or considered, during their pregnancy, or when their child was born. I imagined instead, that there was probably great hope for one's child, in thoughts about the future, and envisioning the simple joy that one must experience when seeing one's child meet the milestones marking the path of human development. I know that parents take great pride in their children's accomplishments and enjoy sharing this information with others. I thought about how for some of these mothers, they would never have this opportunity to have this experience. I thought, "How sad." And at the same time, I thought of how incredibly brave and courageous these mothers are in their fight to attain a quality of life for their children, because I also believed that I could never be as strong as these mothers have been, had I been in their situation.

It was ironic for me to discover how the mental health care system proved to be the adversary in this relationship. By obstructing mothers, the system was also obstructing their attempts to find help for their child. As a clinician, the descriptions of some of these mental health professionals and their actions were embarassing to me, and yet I could understand the theoretical perspective from which they based their actions. The mothers' stories shed tremendous light on how horrible, and awful, and terrible we can be, in our communication with our clients, largely because we have not asked the right questions, and therefore do not fully understand the problems for which they are seeking solutions or support.

From a human and clinical standpoint, conducting this study changed me in my understanding of the phenomenon of motherhood and allowed me to more fully appreciate what it means to raise a child with special needs. Those special needs means that raising a child is an every minute, of every hour, of every day activity for years to come. I applaud these mothers for their strength, courage, and tenacity. I acknowledge their tremendous sacrifice. It has made me more sensitive in my clinical practice to the enormous importance of listening and the need to consciously suspend those perspectives that may limit me in my understanding of the human experience in the clinical problem.

References

Allen, R. I., & Petr, C. G. (1998). Rethinking family-centered practice. American Journal of Orthopsychiatry, 68(1), 4-15.

American Psychiatric Association. (1994). Diagnostic and statistical manual of mental disorders (4th ed.). Washington, DC: Author.

Belcher, J. R. (1988). Mothers alone and supporting chronically mentally ill adult children: A greater vulnerability to illness. Women & Health, 14(2), 61-80.

Bulgur, M. W., Wandersman, A., & Goldman, C. R. (1993). Burdens and gratifications of caregiving: Appraisal of parental care of adults with schizophrenia. American Journal of Orthopsychiatry, 63(2), 255-265.

Caplan, P. J., & Hall-McCorquodale, I. (1985). Mother-blaming in major clincal journals. American Journal of Orthopsychiatry, 55(3), 345-353.

Carter, B., & McGoldrick, M. (1989). The changing family life cycle: A framework for family therapy (2nd ed.). Needham Heights, MA: Allyn and Bacon.

Center for Mental Health Services (1997). Estimation methodology for children with a serious emotional disturbance. Federal Register, 62 (193), 5213-52145.

Chesla, C. A. (1989). Parents' illness models of schizophrenia. Archives of Psychiatric Nursing, 3(4), 218-225.

Chesla, C. A. (1991). Parents' caring practices with schizophrenic offspring. Qualitative Health Research, 1(4), 446-468.

Eakes, G. G. (1995). Chronic sorrow: The lived experience of parents of chronically mentally ill individuals. Archives of Psychiatric Nursing, 9(2), 77-84.

Doherty, W. J., & Baptiste, D. A., Jr. (1993). Theories emerging from family therapy. In Boss, P. G., Doherty, W. J., LaRossa, R., Schumm, W. R., Steinmetz, S. K. (Eds.), Sourcebook of family theories and methods: A contextual approach (pp. 505-524). New York: Plenum.

Gellerstedt, M. E., & leRoux, P. (1995). Beyond anticipatory guidance: Parenting and the family life cycle. Pediatric Clinics of North America, 42(1), 65-78.

Greenberg, J. S. (1995). The other side of caring: Adult children with mental illness as supports to their mothers in later life. Social Work, 40(3), 414-423.

Howard, P. B. (1994). Lifelong maternal caregiving for children with schizophrenia. Archives of Psychiatric Nursing, 8(2), 107-114.

Minuchin, S. (1974). Families and family therapy. Cambridge, MA: Harvard University Press.

Modrcin, M. J., & Robison, J. (1991). Parents of children with emotional disorders: Issues for consideration and practice. Community Mental Health Journal, 27(4), 281-292.

Mrazek, D. A., Mrazek, P., & Klinnert, M. (1995). Clinical assessment of parenting. Journal of the American Academy of Child and Adolescent Psychiatry, 34(3), 272-282.

National Institute of Mental Health. (1993). Learning disabilities (NIH Publication No. 93-3611). Washington, DC: U.S. Government Printing Office.

Pickett, S. A., Cook, J. A., & Cohler, B. J. (1994). Caregiving burden experienced by parents of offspring with severe mental illness: The impact of off-timedness. Journal of Applied Social Sciences, 18(2), 199-207.

Ryan, K. A. (1993). Mothers of adult children with schizophrenia: An ethnographic study. Schizophrenia Research, 11, 21-31.

Sommerfeld, D. P. (1989). The origins of mother blaming: Historical perspectives on childhood and motherhood. Infant Mental Health Journal, 10(1), 14-24.

Strauss, A., & Corbin, J. (1990). Basics of qualitative research. Newbury Park, CA: Sage.

Thomasgard, M., & Metz, W. P. (1993). Parental overprotection revisited. Child Psychiatry and Human Development, 24(2), 67-80.

Tuck, I., du Mont, P., Evans, G., & Shupe, J. (1997). The experience of caring for an adult child with schizophrenia. Archives of Psychiatric Nursing, 11(3), 118-125.

Wahl, O. F., (1989). Schizophrenogenic parenting in abnormal psychology textbooks. Teaching of Psychology, 16(1), 31-33.

Webster's Encyclopedic Unabridged Dictionary of the English Language. (1989). Avenel, NJ: Grammercy Books.

Weiss, S. J. (1991). Stressors experienced by family caregivers of children with pervasive developmental disorders. Child Psychiatry and Human Development, 21(3), 203-216.

Wynne, L. C. (Ed.). (1988). The state of the art in family therapy research: Controversies and recommendations. New York: Family Process Press.

Appendix A

Letter

November 25, 1998

Dear OFSN Executive Board:

My name is Betty Ang and I am a doctoral candidate in nursing at the Oregon Health Sciences University. I currently am working on my dissertation research. This letter is a request for assistance from Oregon Family Support Network in recruiting participants for my research study.

The purpose of this study is to explore how mothers manage the care of children and adolescents with mental disorders, and, from their perspective, how their management of care has been labeled "overinvolved" by mental health professionals. The idea for this study came in large part from mothers who have attended the Salem family support group, in which I have participated as an assistant to the family coordinator, over the past three years. These mothers have frequently described being so labeled and have expressed a desire to have their experience described in a systematic way.

People will be eligible to participate if they: a) are birth or adoptive mothers of a child, between the ages of birth and 21 years, who has been diagnosed with a mental, emotional, or behavioral disorder which meets diagnostic criteria specified in the Diagnostic and Statistical Manual of Mental Disorders, fourth edition; b) identify themselves as having been labeled "overinvolved" (or "overprotective") by a mental health professional on at least one occasion; c) have legal and custodial responsibility for the care of their child; d) are themselves between the ages of 21 and 65 years; e) speak English; and f) live within a 50-mile radius of Portland, Oregon. Mothers may or may not be living with the child at the time of the study.

Oregon Family Support Network may publicize this study by word of mouth and newsletter. People interested in participating may contact Oregon Family Support

Network or be given my phone number to contact me directly. I will contact those selected to explain the study and invite the mother to participate. Prior to any interviews, participants will be given sufficient time to read the consent form, to have procedures and risks explained, and to ask questions about the study prior to signing. Participants will be given a copy of the signed consent form. Participants may withdraw from the study at any time and data relating to her participation in the study will be destroyed.

All consent forms, field notes, tape recordings, and computer files will be kept confidential, locked and unavailable to anyone other than faculty on my dissertation committee.

My dissertation proposal has already been approved by the Oregon Health Sciences University Institutional Review Board who is charged with the responsibility to protect the rights and welfare of human subjects who are recruited in research activities conducted under the auspices of the University.

I would be happy to answer any questions or meet with members of the Board. Thank you for your consideration of my request.

Sincerely,

Betty Ang, RN, MSN, CS, PMHNP
(503) 945-7132 (work)
(503) 581-9498 (home)

Appendix B

Consent Form

OREGON HEALTH SCIENCES UNIVERSITY

Consent Form

TITLE: Mothers Labeled "Overinvolved": How They Care for Children and Adolescents with Mental Disorders

PRINCIPAL INVESTIGATOR: Sheila M. Kodadek, Ph.D., RN, Principal Investigator, (503) 494-3826; Betty Ang, RN, MSN, CS, PMHNP, Co-Investigator, (503) 581-9498.

PURPOSE: Betty Ang, a doctoral student at the Oregon Health Sciences University School of Nursing, is conducting a research study on how mothers manage the care of children and adolescents with mental disorders and, from their perspective, how their care has been labeled "overinvolved" by mental health professionals. You have been invited to participate in this research study because of the information you can provide on these experiences. Your information may help mental health and other health care professionals improve their services to parents of children and adolescents with mental disorders. The length of time you will be involved with the study is approximately 6 to 9 months.

PROCEDURES: You will be interviewed at least twice and, at most, three times. The interviews will take place in your home or at a location of your choice. The first interview will last between one and two hours. Questions during this interview will focus on your child's care, how you manage that care, your experience of being labeled "overinvolved," and how that label affected you. You also will be asked to provide information about your age, your child's age and diagnosis, and other basic demographic information. The purpose of the second and, if necessary, third interviews primarily will be to clarify statements you made in the first interview. The second and third interviews will last approximately one hour each. All interviews will be audiotape recorded. This consent form will be reviewed prior to each interview and your continued agreement to participate will be recorded on the audiotape.

RISKS AND DISCOMFORTS: You may feel uncomfortable answering personal questions. However, you may stop the interview, ask to continue the interview at another time, choose not to answer any question, or withdraw completely from the study. If you withdraw from the study, your data will be destroyed.

BENEFITS: You may or may not benefit personally from participating in this study. However, by being a participant, you may contribute new information which may benefit other parents in the future.

ALTERNATIVES: You may choose not to participate in this study.

CONFIDENTIALITY: Neither your name nor your identity will be used for publication or publicity purposes. According to Oregon Law, suspected child abuse must be reported to appropriate authorities. Audiotape recordings of your interviews will be kept in a locked file cabinet. Audiotape recordings of your interviews will be listened to only by the Principal Investigator or Co-Investigator, and will be destroyed, along with any written transcripts of your interviews, when the study is completed.

COSTS: There are no costs to participating in this study, nor will you be compensated for your participation.

LIABILITY: The Oregon Health Sciences University, as a public corporation, is subject to the Oregon Tort Claims Act, and is self-insured for liability claims. If you suffer any injury from this research project, compensation would be offered to you only if you establish that the injury occurred through the fault of the University, its officers or employees. However, you have not waived your legal rights by signing this form. If you have further questions, please call the Medical Services Director at (503) 494-6020.

PARTICIPATION: Betty Ang, (503) 581-9498, has offered to answer any questions you may have about this study. If you have any questions regarding your rights as a research subject, you may contact the Oregon Health Sciences University Institutional Review Board at (503) 494-7887. You may refuse to participate, or you may withdraw from this study at any time without affecting your relationship with or treatment at the Oregon Health Sciences University or other health care facility. You will be informed of any new findings that may affect you or your wish to continue participation. If you sign, you will receive a copy of this consent form. Your signature below means that you have read the information above and agree to participate in this study.

____

Subject Date

____

Witness Date

Appendix C

Demographic Information

Date of Interview: ______________________________

Demographic Information

1. Mother's Age in years: __________

2. Child's Age in years: __________

3. Child's Diagnosis/Diagnoses: ____

   ____

4. Child's Length of Involvement with Mental Health Services: __________ months

   OR __________ years

For the following, please **circle the letter of the item that best describes you for each category**.

5. Marital Status:
   - a. Married/Partnered
   - b. Separated
   - c. Divorced
   - d. Widowed
   - e. Never Married

6. Ethnicity:
   - a. White
   - b. African-American
   - c. Hispanic
   - d. Asian
   - e. Native-American
   - f. Middle-Eastern
   - g. Other

7. Your Highest Education Level:

a. 8th grade or less
b. Grades 9 to 11
c. High school diploma
d. Some college
e. College degree
f. Some graduate education
g. Graduate degree

8. Annual Income (Which of the following best describes your total annual household income):

a. Under $3,000
b. $3,000 to $5,999
c. $6,000 to $9,999
d. $10,000 to $14,999
e. $15,000 to $19,999
f. $20,000 to $29,999
g. $30,000 to $39,999
h. $40,000 to $49,999
i. $50,000 and over

Appendix D

Interview Guide

Interview Guide

As you know, the purpose of my study is to talk with mothers about how they manage the care of their child with a mental, emotional, or behavioral disorder and to explore mothers' experiences of being labeled "overinvolved" by mental health professionals regarding the care of their child. The idea for this study actually comes from my participation in a family support group and the mothers' concerns about being labeled "overinvolved" or "overprotective" by mental health professionals. I would like to learn more about other mothers' experiences.

1. First of all, what is your child's name? How old is (name)? Could you tell me a little bit about (name)?

2. (If diagnosis is not revealed during the first question) What is (name)'s diagnosis? How has (name)'s (diagnosis) affected how you've had to care for him/her?

   Probe: How do you think the (diagnosis) affects how (name) functions in his/her everyday life?

   Probe: What kinds of things do you think about when you make decisions about (name)'s care?

3. What was it like taking care of (name) when he/she was younger?

   Probe: What were some of the things you had to do to take care of (name)?

4. Has taking care of (name) changed over time? Can you describe this for me?

   Probe: How has (name) changed? Can you tell me of some incidents?

5. In what ways is (name) like other (age) year olds? How is he/she different? Do you think that those differences are due to (name)'s (diagnosis)?

6. What are some of the things you have had to do for (name) that you think other parents don't have to do whose children do not have an emotional, behavioral, or mental disorder?

7. You have been described as "overinvolved" by a mental health professional regarding the care of (name). Would you describe the situation in which that happened?

Probe: What were the circumstances? What do you think led to being described as "overinvolved"? How did you feel about it? What did you do after that?

8. How did this experience affect your relationship with that particular mental health professional?

9. How has being labeled "overinvolved" affected your relationships with other mental health professionals with whom you have since worked?

10. Has it changed your parenting behaviors with (name)?

11. How has being labeled "overinvolved" affected your relationship with other family members?