To the Graduate Council:

I am submitting herewith a dissertation written by Josephine Wade entitled "Crying alone with my child": An existential phenomenological exploration of the meaning of being a parent of a school age child with Bipolar Disorder. I have examined the final paper copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Nursing.

Sandra Thomas

Dr. Sandra Thomas, Major Professor

We have read this dissertation

And recommend its acceptance:

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Vice Provost and Dean of

Graduate Studies

"CRYING ALONE WITH MY CHILD:"

AN EXISTENTIAL PHENOMENOLOGICAL EXPLORATION OF THE MEANING OF BEING A PARENT OF A SCHOOL AGE CHILD WITH BIPOLAR DISORDER

A Dissertation

Presented for the

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Degree

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Josephine Wade

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ABSTRACT

Recent years have seen a rise in the number of children diagnosed at an early age with bipolar disorder. Additionally, prescription of psychiatric medications to young children has sharply increased. Parents must assume the responsibility for medication management and behavioral monitoring because inpatient care is brief. This, combined with a changing political arena, may mean continued stress and burden for caregivers and parents of children diagnosed with a psychiatric illness.

The purpose of this existential phenomenological study was to describe the lived experience of parents of children ages 6-11 years, who are diagnosed with Bipolar Disorder. An existential phenomenological research method was used. Non directive, in depth, taped interviews were conducted with a volunteer sample of 10 parents. The narratives were analyzed for common themes of experience by the researcher and an interdisciplinary research team.

A thematic structure of four interrelated themes emerged. These themes were: (1) "it's always, always: engulfed in chaos"; (2) "my hands are tied: scared and frustrated"; (3) "on the other side of a dark curtain: alone and shunned away"; and (4) "I cry so many tears on this child: it hurts but it's worth it." The themes stood out against the contextual ground of others, primarily the child and professionals in the educational and health systems. The parents in this study experienced unrelenting fear, frustration, loneliness, and hurt. The health and educational systems proved to be inadequate. However, the parents were strong, fighting for the rights of their child, the prime consideration of their lives.

Examined from the perspective of family nursing care for a chronically ill child, the study informs nurses of ways to support parents. The findings also provide further insight into the interactions that the families have with the environment with implications for a wider audience of school, medical, psychiatric, social work, and psychological professionals.

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CHAPTER I

INTRODUCTION

Introduction

As morning breaks all over the world parents are getting their children off to school. For most it's a scramble to fix lunches, feed the children breakfast, gather up the homework and off to school they go, but for a certain group of parents things are not as simple. They may have been up all night with a child who was suddenly terrified by an innocuous object in the hallway outside their door, their child may have paced around most of the night and now be in a deep almost comatose sleep difficult to roust, or they may be faced with a vicious verbal tirade directed towards the parents. These are the parents whose children have a psychiatric health disorder. This study describes the lived experience of parents with elementary school age children who have a psychiatric illness called Bipolar Disorder.

Scope of the Problem

The number of parents who have children with psychiatric illness is significant and growing. Bipolar Disorder is one of a range of psychiatric illnesses that have a disturbance of mood as the predominant feature, divided into Depressive Disorders, Bipolar Disorders and two disorders based on etiology: Bipolar Disorder due to a General Medical Condition and Substance Induced Bipolar Disorder (American Psychiatric Association, [APA] 2000). Depressive disorders are distinguished from Bipolar Disorders by the fact that there is no history of the individual ever having had a manic episode (APA, 2000).

Epidemiological data specifically on Bipolar Disorder in prepubertal children is scant, with estimations ranging from 1% to 5%. However, there is increasing evidence that

prepubescent early onset Bipolar Disorder is a significant problem and occurs in children as young as toddlers (Geller & Luby, 1997; Lewinson, Klein, & Steele, 1995; McLure, Kubiszn, & Kaslow, 2002; Papolos & Papolos, 2001). In the United States the prevalence of Bipolar Disorder is approximately 1% of preschoolers, 2% of elementary and middle school children and 5-8% of adolescents (Son & Kirschner, 2000).

Childhood Bipolar Disorder, like that seen in adults, affects all socioeconomic levels and ethnic groups. There is strong evidence that it is highly heritable, although results of research into biomarkers are inconclusive in children (Birmaher, Ryan, William, Brent, Kaufman, & Dahl, et al., 1996). In those younger than 9 years old Bipolar Disorder generally presents as depression with mania. Mania exhibits as extreme irritability and emotional lability. As the child reaches ages 9 years and over it presents as depression, classic euphoria, elation, paranoia, and grandiosity (Center for Mental Health in Schools [CMHS], 2003). Bipolar Disorder in children is also characterized by intense, long lasting rage (Mohr, 2001). Depression in children manifests as a two-week (or greater) change in emotion and behavior such as sadness, crying, hyperactivity, motivation, changes in appetite, sleep, or health, and feelings of hopelessness (APA, 2000). However, both under diagnosis and co-morbidity are associated with this disorder (Birmaher et al., 1996.; Costello et al. 2002; Geller & Luby, 1997; Papolos, & Papolos, 2001). Theory of causation continues to split into either a substantial genetic component or problems with early caregiving relationships, but there is increased understanding of the combined effects (Geller et al, 1995; Johnson, Cohen, Smailes, & Brooke, 2001; Fristad, Weller, & Weller, 1992; Wozniak et al. 1995).

Bipolar Disorder that goes untreated can result in suicide, the third leading cause of death for 15 to 24 year olds and the sixth leading cause of death for five to 15 year olds. It is notable that the rate of suicide for ages 10-14 increased by 109% between the years 1980-1997 (Center

for Disease Control, [CDC] 2003). According to a study of 79 depressed children conducted over a two to five year span almost one-third of six- to twelve-year-old children diagnosed with major depression will develop Bipolar Disorder within a few years (Geller, Fox, & Clark, 1994). This is a significant finding considering that it is estimated that 21% of children age nine to seventeen experience the signs and symptoms of a psychiatric disorder during the course of a given year with depression the third most common disorder in this age range, affecting 6 out of 100 children (Birmaher, et al., 1996).

Bipolar Disorder is a chronic illness that occurs at similar frequencies as other childhood chronic conditions. For example the incidence of Juvenile Diabetes is 1:400, Cystic Fibrosis 1:3,000 in whites, 1:12,000 in blacks, and asthma 1:20 (CDC, 2003). Yet two-thirds of children with psychiatric health problems do not get the help they need, even though many of the disorders respond well to treatment (CMHS, 1996). Successful management of the illness is unlikely without the involvement of the parents. This study may help to illuminate how to best target strategies to help parents combat the problem of childhood Bipolar Disorder.

Historical and Experiential Context of the Study

The researcher's interest in studying the experience of parenting a child in their middle years with Bipolar Disorder evolved from both professional and personal experiences. During her professional career as a pediatric and family nurse in hospital and community settings, and as a nurse advisor for a special education parents group, the researcher frequently observed the severe difficulties that parents of children with emotional disorders encounter. Discussions with school-based nurses and nurse practitioners revealed that children with psychiatric health problems were considered one of the top two most significant problems that they encountered (the other was asthma). This is supported in the literature (Adelmann, Taylor, Bradley & Lewis, 1997;

Adelmann & Taylor, 2000; Barrett, 2000; Dickson, 2001). In addition, the researcher's personal experience as a mother of a child who was diagnosed with major depressive disorder at age 20 years after a long illness brought to light deficiencies in the health care system and lack of support and understanding in the community. With this in mind the researcher studied the literature to see what the current state of the problem is and what the nursing profession is doing to address the problem.

Childhood psychiatric health is presently at the center of an intense national debate. In January 2000, David Satcher, MD, Ph.D., Assistant Secretary for Health and Surgeon General, reported a health crisis caused by the burden of suffering of children with psychiatric health needs and their families, stating that there is no primary psychiatric health care for children (US Public Health Service, 2000). The President's New Freedom Commission on Psychiatric Health (2003) report is evidence of governmental determination to confront the hidden suffering of Americans with psychiatric illness, but the report noted that there has not been any significant progress over the past three years. Grass roots advocacy groups are spreading, as parents of children with psychiatric and behavioral health problems demand their legal rights for a fair and appropriate education for their children and search for help with securing their children's futures. Nevertheless, for these parents the struggle through the barriers to care is often unbelievably arduous and complex.

Summary of Literature

Parenting a Child with a Psychiatric Illness

Most of the studies on parenting a child with a psychiatric illness focus on the adult child and reveal unique and challenging aspects of parenting a psychiatrically ill individual. Some of the parenting tasks identified in these studies are staying emotionally connected with the ill child,

retaining a sense of self and hope, and finding a way through the elaborate systems of care and treatment regimes (Doornbos, 2002; Pejlert, 2001; Rose, 1998; Saunders & Byrne, 2002). In addition, several studies of parents with psychiatrically ill adult children have found inadequacies in the health care system and problems in the interactions that parents have with psychiatric health care providers (Delaney & Engles-Scianna, 1996; Doornbos, 2001; Moore & Beckwitt, 2003; Pejlert, 2001; Rose, 1998).

One way that parents retain a sense of self and hope is through seeking out fulfillment through their parenting experience. Shwartz and Gidron (2002) explored the fulfilling and positive aspects of parenting. One parent from each of 93 households who were caring for an adult child with a psychiatric illness completed measures of the adult child's contribution to the family, gratifications of caregiving, and burden. Hierarchical regression was conducted for each type of reward. Parents found many gratifications in their caregiving, the highest being sense of satisfaction from fulfilling their parental duties and developing inner strength. The participants saw themselves as receiving emotional support from their children significantly more often than instrumental support ($p < .001$). An interesting finding in Shwartz and Gidrons' (2002) study was that high burden was not related to low gratification, even though high levels of daily hardships were positively related to perception of low support from their children. Demographic variables were unrelated to the results. This study, conducted in Israel, provided evidence of the positive outcomes of caring for a psychiatrically ill child, as do others in the comprehensive review of literature in Chapter II.

As mentioned previously, finding their way through the social, educational, and health care systems is difficult for parents. A sizeable number of psychiatrically disabled people live with relatives and depend on the family to take on caregiving responsibilities. Norbeck, Chafetz, Skodol- Wilson, and Weiss (1991) analyzed the content of qualitative interview data in sixty

family caregivers from three age groups. Norbeck, et al (1991) found that parents of both child and adult offspring had reorganized their lives around the caregiving demands. However, the findings of this study blur in relation to the current study because although the diagnoses of the adult children of the participants were Bipolar Disorder and Schizophrenia the younger children were diagnosed with pervasive developmental disorder. Nevertheless, for all three groups the highest frequency of need reported by parents was for information about the illness.

Studies with caregivers of adult bipolar or schizophrenic patients showed a consistent pattern reflecting extreme lack of health provider support for the families (Hobbs, 1997; Howard, 1998; Rose, 1996; Saunders, & Byrne, 2002). As parents of young children with Bipolar Disorder are facing stressors over the long term, this is not encouraging news. A common perception among families is that they are not getting the psychiatric health care that they need (Delaney & Engles-Scianna, 1996; Starr, Campbell & Herrick, 2002, Scharer, 2002; Stubblefield & Murray, 2002). Consequently, their sense of self worth in the community may be threatened. Also, the behaviors that the children may exhibit can be rejected by the community at large, marginalizing the family, reducing social support, and decreasing the child's sense of worth (Geller & Luby, 1997, McCoy, 1998; Papolos & Papolos, 2002, Wu et al., 2001).

Therefore, families and children are undoubtedly suffering and the consequences of untreated childhood psychiatric health problems augur serious societal ramifications. Families struggle with the inefficiencies of the psychiatric health system, experience dissatisfaction and a perceived lack of trust in health care professionals, and suffer stigma and blame. Studies have measured parents' coping skills, social support, level of depression, and parenting styles (Doornbos, 2001; Doornbos, 2002; Scharer, 2002; Stubblefield & Murray, 2002), but few have looked at their experience holistically. A new line of research related to parenting is examining the long held supposition that having a depressed parent is the main cause of childhood

depression, proposing instead that it is the experience of parenting the sick child that is deleterious to the parents (Birmaher et al., 1996). Child psychiatric disorder is strongly linked with "end of one's rope" syndrome in parents and caregivers that may be the cause and /or consequence of the child's condition (Costello, Keeler, & Angold, 2001, p.1497).

Carr (2001) states that it is now timely to focus attention on Bipolar Disorders in children because attention deficit and conduct disorders have received much attention. As Bipolar Disorders are being identified at an earlier age (Labellate, Ginsburg, Walkup, & Riddle, 1999) parents have a greater burden to adhere to a complicated regime of treatment. Hospitalizations are typically only three days to two weeks, counseling is often only provided monthly, and there is still an inequitable cap on psychiatric illness insurance compared to physical illness insurance. That leaves the parents doing the bulk of behavioral training and medication monitoring, which is a substantial task given the paucity of services and the complexity of treatment. Consequently, there is a high incidence of premature termination of treatment in these families (McClure, et al., 2002). Saunder's (2003) literature review on studies of families living with mental illness revealed that as stressors persist over the long term, caregivers' depressive symptomatology may worsen. Clearly, there is a higher incidence of physical illnesses, depression, anxiety, substance abuse, and personality disorders in parents of psychiatrically ill children than the general population, although the evidence is not clear if this is comes before or after the child's illness (Birmaher et al, 1996).

The focus of the present study is the experience of parenting a younger child, between the ages of 6-11, diagnosed with Bipolar Disorder. Very few studies have addressed this age group, which has unique developmental and parenting needs. The next section examines theory and contemporary issues that pertain to this age group.

The Child in the Middle Years

Middle childhood is the time for increasing skills in knowledge and play. In order to meet the expectations of society the child needs and wants real achievement, and is learning the rules, gaining a sense of competency, beginning to understand logic, law and order, and the good girl/boy orientation. This is the stage that Piaget (1962/1985) describes as the concrete operational period where an egocentric outlook is replaced by the beginnings of empathy. These children are learning physical skills, building wholesome attitudes towards themselves, learning to get along with friends, developing conscience, morality, and values, and starting to achieve personal independence (Havighurst, 1952). Known also as the latency period, a term first used by Sigmund Freud (1866/1959), there is increasing intensity of emotions and impulses in the elementary school years. The development of the superego or internal conscience can forebode a frustrating and anxious time for 6-7 year olds (Davies, 1999).

Current child development theory was developed from a strong base of well known psychological theorists. However failure of these theories to explain the full complexity of development has led to a general acceptance of multifactor theories. One of these is the Transactional Model of Development (Sameroff & Chandler, 1975). Research has demonstrated that the child's transactions with the environment influence their development from birth, which partially explains the different outcomes in those with biological and genetic similarities. The transactional model considers the parent to be important in shaping the transaction but also recognizes the bi-directional interactions between the child and caregiver. Thus, social factors may both influence and alter the parent/child relationship.

Another model used consistently in middle childhood studies is the ecological model of human development (Bronfenbrenner, 1977). This model is appropriate for understanding the school age child as they move outside of the family context to enter the wider influence of

community, media and school, further complicating the child's transactions. Congruent with these contemporary models is Bowlby's (1988) concept of developmental pathways whereby external forces in the environment such as trauma, poverty, or conversely, a move to a better school may move the child into a different path of development. Therefore the environment is very important during the years between six and eleven, a very critical period of the child's' development, as they learn the rules of the larger world and develop a clearer sense of self. According to Schroeder and Gordon (2002), "a transactional dialogue continues in each child with his /her unique biological /genetic makeup, the physical and social environment and the current milieu into which he or she is born" (p.3). This makes the era in which the child is living very important.

The contemporary child is bombarded with violent media, schools have been infiltrated with illegal drugs and weapons, and poor social models are prevalent. Several studies have shown the adverse effects of direct and indirect violence on young people; among these effects are anxiety, depression, and post traumatic stress disorder (Bushman, & Anderson, 2001; Jones, 1997; Sheehan, Kim, & Galvin, 2004; Youngstrom, Weist, & Albus, 2004). For latency age children both vertical relationships (attachment to individuals with knowledge and power) and horizontal relationships (peers) are important. They identify with real people as heroes and role models; these include parents, teachers, sports figures, and older admired children (Davies, 1999). Academic demands and fantasy play increase; it is not uncommon for school children to reenact movies, violent or otherwise, as a tool to support their increasing wish to be powerful and competent. These children are very vulnerable to anxiety, embarrassment, and self-doubt. Increasing skills of abstract thinking makes their sense of themselves increasingly dependent on how they think others, especially their peers, perceive them (Schroeder & Gordon, 2002).

Good individual or agency supports are protective factors for increased resilience against social and psychological instability in middle childhood. These supports include adequate child

care resources, low stress, consistent stable home environment, high IQ, responsive parenting, high nurturance, consistent discipline, and high expectations. Life stresses and daily hassles can have a negative effect on child adjustment because they deplete the resources of parents as well as the children . Also, if intense parental help is needed in treatment regimes the child can become overly dependent on the parents (Schroeder & Gordon, 2002).

Children with emotional or learning difficulties are particularly susceptible to societal changes. A genetically coded susceptibility may put some at exceptionally high risk if they are exposed to overwhelming stress (Siegel, 1999). According to Birmaher et al (1996) children with Bipolar Disorder exhibit perceived lack of control over negative events and lower coping with stress than well children. Their volatility, impulsiveness, and aggressiveness may make them unpopular with peers, portending the beginnings of rejection by positive peer groups. Consequently, they are vulnerable to the long term consequences of social rejection, such as delinquency, dropping out, and other psychiatric disturbances.

Most of the studies that purport to include emotional disorders in children are conducted with children with developmental delay, mental retardation, or adolescent substance abuse. As there is so little empirical research with the younger child with Bipolar Disorders, this area remains to be explored. Studies are needed in order to see if the findings in adult offspring studies generalize to the population of parents of younger children with Bipolar Disorders. The phenomenological method used in this study described the parent's total experience in the family, community, and environment, adding to the literature, and extending what is known about the experience of parents with young children with Bipolar Disorder.

Research Problem

Because past studies have overlooked a holistic perspective we do not know the whole essence and meaning of the parenting experience when a child has a Bipolar Disorder. Multiple studies have described concepts such as stress and coping but these only give us snippets of information and lack a holistic ecological perspective. As parental coping and adaptation is well documented in quantitative studies, Hays (1997) concludes that qualitative studies related to childhood chronic illness hold promise for helping us understand the parenting experience. Hays (1997) states that "knowledge in no single conceptual area even scratches the surface of what health care professionals need to know to design effective, sensitive care" for these parents (p. 278). She also feels that researchers and clinicians are working in isolation and she states that there is much need for research that illuminates interrelationships in the family and identifies the positive effects of living with a child with a chronic condition. In a response to Hays' (1997) synthesis, Deatrick (1997) reiterates the responsibility of nurse researchers to listen to families' stories. An additional problem is that many studies are conducted in a laboratory or clinic setting. According to Denham, (1999) it is important in family health research to include the contextual settings where people live and work.

Partly because of vulnerability issues there is a paucity of studies on chronic illness in young children and the "tween" years, the ages between 9-13 (Charron-Prochowik, 2002) and a larger scope of children's disabilities should be looked at (Nelson, 2002). There is a notable lack of inclusion of children with psychiatric illness, especially ages birth to prepubescance, in child disability studies. Additionally, many of the studies were done in a different era and may have limited relevance when viewed in the light of current times (Rose, 1996). Very few studies in nursing have focused on the experience of parents with a troubled child or adolescent and none have explored the lives of those parents with a child age 6-11 diagnosed with a Bipolar Disorder.

Purpose Statement

The purpose of this existential phenomenological study was to describe the lived experience of parents of elementary school age children who have been diagnosed with Bipolar Disorder.

Research Question

What is the meaning of parenting an elementary school age child who has been diagnosed with Bipolar Disorder?

Definitions

1. Parent: an individual who undertakes major care giving roles for the child on a daily basis and who lives with the child. This includes biological and adoptive parents, stepparents, partners of parents, older siblings, and grandparents.

   Rationale: Definition of parent, "One who begets, gives birth to, or nurtures and raises a child" (The American Heritage Dictionary of the English Language, 2000. p. 879).
2. Bipolar Disorder: Using symptom criteria in the DSM IV-TR, and/or DSM-PC.
3. School age child: ages 6-11 years.

   Rationale: A broad range of theory defines "middle childhood" as extending from age 5 to the onset of puberty, between the ages of 10 -12 years. The researcher chose 6-11 to limit the influence of the transitional stages of kindergarten and puberty.

Delimitations

1. Participants were purposefully selected from communities in Alabama and Tennessee.
2. Participants were over 18 years old and English speaking.

3. Participants volunteered to participate in the study, were cognitively able to participate in an interview, and were not be in significant emotional distress at the time the interview commences.
4. The child had been diagnosed with a Bipolar Disorder by a psychiatrist.
5. The child did not have significant developmental delay as defined by DSM IV-TR.
6. The child was not abusing substances or had chemical addictions.

Significance of the Study

The number of American children between the ages of 6-17 years old approaches being the largest ever; by 2010 it will reach the largest at 48 million (National Assembly on School Based Health Centers [NASBHC], 2002). In addition, the incidence and prevalence of childhood Bipolar Disorders is increasing (Birmaher et al., 1996). Consequently, the number of parents caring for these children will be substantial. Parents, rather than institutions, have become the major providers of the long-term psychiatric health care necessary for many children with Bipolar Disorder. Therefore, it is very important that these parents receive appropriate nursing care.

The past ten years have seen a rise in the number of children diagnosed at an early age with Bipolar Disorder. Additionally, prescription of psychiatric medications to young children has sharply increased (Jellinek, 2003). This, combined with a changing political arena such as "no tolerance" school behavior policies, and low funded community-based psychiatric health care, means continued caregiving stress and burden for parents of children diagnosed with psychiatric illnesses. Goals of *Healthy People 2010* (U.S. Department of Health and Human Services, 2000) include decreasing the number of childhood suicides, and decreasing lost days at school because of emotional problems. This study contributes to the gap in knowledge about the experience and needs of the family in the current political and social climate.

This study has implications for school based nurses and Advanced Practice Nurses (APNs) who are often the first professionals to identify that the child has serious depressive symptoms such as suicidal thoughts (Adams, Shannon, & Dworkin, 1996; Adelmann, et al., 1997; Simpson & Young, 1998; Weiss & Christoduli, 2000). It is imperative that as nurses we understand what the parents are dealing with on a daily basis in order that we better meet their needs. This study increases the level of understanding available to school health personnel about parents' needs in the school environment.

Caring for families of children with Bipolar Disorders is clinically relevant to school nurses, pediatric nurse practitioners, family nurse practitioners, psychiatric nurse practitioners, occupational health nurses, community health nurses, and case managers, as well as other professionals. The existential phenomenological method used in this study allows parents to tell the story of their experience in their own words. By listening to the parents' words nurses will understand the parents intimately and holistically with increased empathy. An improved understanding of the needs of parents will help nurses develop practice interventions that may include education and giving positive reinforcement and support to the parents.

Exploring the parents' experience has important implications for communities at large and implications for health policy. The findings provided additional evidence for increasing training of nurses in pediatric psychiatric nursing and for more school based nurses with an interdisciplinary and multidisciplinary focus. This study conceptualizes the family as the primary environment for care of the child and the health care system, including nurses, as the primary caregiver for the family, within the confines of the larger multiple community systems.

Summary

This study provided a unique and important contribution to nursing knowledge on the parents' lived experience with a child who has Bipolar Disorder. The holistic perspective gave further insight into the interactions that the families have with the environment and community with implications for a wider audience of school, medical, psychiatric, social work, and psychological professionals. The uses of existential phenomenology in this study sought to unfold the essence of what it meant to parent these special children who were growing up while at the same time undergoing an emotionally painful illness. This chapter provided information to support the need for the study and an overview of the research project. Chapter II will provide a review of current literature related to family health care and parenting children with chronic physical and psychiatric illnesses.

CHAPTER II

LITERATURE REVIEW

Introduction

The focus of family nursing concern includes the individual in interaction with other family members, the family unit as a whole, and the family as an integral part of the community. This literature review begins with an examination of the development of family related research and nursing care, including a brief historical perspective. The main focus of the chapter is to discuss the challenge of parenting a sick child, culminating with a critique of current research that examines the family with a child who has been diagnosed with a psychiatric illness.

Various strategies were used to search the literature. Meta-analyses and seminal research articles prior to 1990 were reviewed. Computer searchers of the Cumulative Index to Nursing and Allied Health Literature, PsycInfo, and Medline were used for key topics of family and parents with children with chronic physical and psychiatric illnesses. Hand searches were performed for the current content of nursing journals and references explored from these articles. Although much of the background investigation included multidisciplinary studies this review is almost exclusively a review of nursing literature pertaining to aspects of family life with a sick child.

Family Nursing

Over the past 20 years family nursing has emerged as a distinct specialty of nursing research and practice. Today there is a growing realization that unexpected acute and chronic health problems produce family distress (Friedmann, Bowden, & Jones, 2003). Commonly, the family is conceptualized at three levels. One level views the individual in the context of the family; the second level conceptualizes dyads, such as parents, partners, mother and child; and

the third level includes the macro system of the family in a cultural and environmental context (Friedmann, 1993).

Family nurse researchers make a distinction between categories of normative and non-normative transitions (Friedmann, et al., 2003). Normative refers to the developmental tasks and processes that most families become involved in as they pass through their life's course, while non-normative refers to the multitude of out of the ordinary health challenges that families experience, which places extra burden and stress on them. Studies of non-normative transitions have traditionally focused on the impact of illness and efforts in the family to adapt (Feetham, 1999). Because the proposed study will describe the experience of parenting a child who has been diagnosed with a potentially chronic psychiatric illness, specifically Bipolar Disorder, this review concentrates on the nursing literature relating to nursing care of families in non-normative transitions.

Several categories of participants in family nursing research were identified by Gilliss and Knafl (1999) in a comprehensive review of the state of family nursing science and practice regarding non-normative families during the time frame 1984 to 1996. These were mothers, elders, caregivers, couples, parents, family, and spouses. The major health problems under study identified were AIDS, asthma, bronchopulmonary displasia and preterm infants, cancers, cardiac, chronic illness, conduct disorders, critical care, cystic fibrosis, death, diabetes, disability, frail elders, cerebral palsy, caregiving, liver disorders, medically fragile children, muscular dystrophy, organ dystrophy, organ donation, pain, schizophrenia, psychiatric health, seizure disorders, technology dependence, temperament and violence. Main phenomena identified in the studies were recovery and transition, familial bonds, caregiving, and parental or familial distress.

The purpose of family nursing is to "promote, maintain, and restore family health; it is concerned with the interaction between the family and society and among the family and

individual members" (Hanson, 1987, p. 8). A definition of "family" continues to evolve as social norms alter. For the purpose of this review and study a contemporary view of the family was taken, as defined by Wright and Leahey (2000) "the family is who they say they are" (p.70). Most definitions of family today are not confined to legalistic or biological distinctions. Friedmann et al. (2003) define family as "two or more persons who are joined together by bonds of sharing and emotional closeness and who identify themselves as being part of a family" (p.10).

Qualitative studies have revealed that how researchers characterize the family is less important than who individuals view as their family (Denham, 1999). With this in mind a broad definition of parent is also deemed appropriate for this literature review and study going beyond parents with biological relationships to those who fit Bronfenbrenner's (1979) definition as being those individuals who are located in the principal context in which child development occurs. Therefore the definition of parent for this review, and for the proposed study, includes the nurturer or caregiver who undertakes day-to-day parenting responsibilities.

History of Family Nursing

In an examination of nursing discourse Whall (1993) found references to family nursing from the time of Florence Nightingale and onwards. While carrying out her mission to help the soldiers of the Crimean War Nightingale realized that their families would also need to be cared for. Early public health nurses were very aware that the sick individual could not be addressed in isolation from the family. According to Whall (1993), family nursing continued to evolve with the 1917 publication of standards for nursing curricula, which included needs of families. From 1930 to the present, family nursing has been included in programs of nursing education. Consequently, Whall (1993) concludes from the historical literature that family nursing is now well established. It is important to note that a distinction is made in nursing between family

research and family related research. This study is family related research because not all of the immediate family are participants. Nevertheless, in order to comprehensively understand the state of family nursing the literature review encompasses both family and family-related studies.

Non-normative Family Transitions

This literature review included all state of the science papers and meta-analyses of research on non-normative family transitions. The findings of these comprehensive reviews were incorporated into the literature review along with more recent studies that were identified in the literature search.

The most recent synthesis of family nursing is Knafl and Gilliss's (2002) appraisal of current research into families and chronic illness. Building on prior reviews the authors examined the state of science in 73 articles related to families facing non-normative health related challenges. Their results revealed two areas of knowledge, which Knafl and Gilliss (2002) named the descriptive and explanatory clusters. The descriptive cluster included mostly qualitative studies, which revealed that families typically rise to the challenge and find positive meaning over time. Other recurrent themes in family responses included normalization, impact on the family, transitions, and stages of adaptation. The explanatory cluster, mostly quantitative studies, identified the nature of the family response situated in the context of other family stressors. However, Knafl and Gilliss's (2002) synthesis revealed a paucity of studies on what factors contribute to the development of differing family responses to illness and the role of the health care professional in shaping the families' responses. In addition, Rose (1996) identified that more research is needed as to whether family functioning is poor because of the sick child's deterioration or vice versa.

Stressors in families with a child with a chronic condition have been the subject of qualitative studies by nurses with many years of family based research. Burke, Kauffman, Costello, Wiskin, and Harrison (1998) prepared a meta-analysis of such studies conducted from 1990-1994. They found that terms such as stressors, tasks, challenges, concerns, and problems are commonly used to describe the parent's experiences. However, out of the 15 studies reviewed only three were related to psychiatric or psychological disorders in the child; two of which were parents of children with developmental disabilities (Snowdon, Cameron, & Dunham, 1994; Strauss & Munton, 1985) and the other had a small cohort within the study of parents whose children had emotional disorders (Petr & Barney, 1993). All other studies were with families with children with physical disorders. The results of the meta-analysis confirm that stress is a well-defined consequence of parenting a sick child.

In a similar metasynthesis Nelson (2002) analyzed 12 qualitative studies relating to mothering other than normal children, finding found four steps common to the mothers' experience. Step one was named "becoming a mother of a disabled child" (p.520) referring to the timing, not always at birth, and emotions surrounding the realization that their children were disabled in some way. Step two refers to "the learning curve" (p.522), a process of learning the "extras" involved in caring for the child, such as negotiating the health care system, absorbing the difference in mother/ child and intra family relationships that may occur, and becoming aware of societal reactions which were often negative. Step three, "dealing with daily life: It will never be the same" refers to caregiver burden, alteration in employment, social isolation, and uncertainty. Step four, termed "the process of acceptance/denial" described the repeated themes of normalcy and the grief surrounding the loss of normalcy. Step four also includes the "embrace of paradox" (p.527), a profoundly descriptive term that expresses emotional coping as being a compromise somewhere between acceptance and denial that the mothers in the studies devised.

Nelson's (2002) synthesis adds to the evidence that the extraordinary pressures of mothering a child with health problems can run the span of a lifetime, involve adaptation over time, and have both positive and negative consequences. Nevertheless, Nelson's (2002) conclusions are limited in that only a small number of studies were synthesized and the focus was on the mother alone. The twelve studies synthesized included only one study of a child with a psychiatric disability, (Attention Deficit Hyperactivity Disorder), two with unspecified disabilities, and one with mothers of adult offspring with schizophrenia.

The concept of family nursing goes further than the now commonly recognized practice of involving parents in their children's care to recognizing that the care-givers as well as the child have needs that should be addressed (Callery, 1997). Therefore the next section discusses literature related to the impact that a child's chronic illness has specific to parents.

Parenting in Non-normative Family Transitions

Research into parenting in non-normative family transition primarily focuses on parents with children with a chronic physical illness. There is no one accepted definition of childhood chronic condition. Anderson, Anderson, & Glanz (1998) define chronic illness as, "any disorder that persists over a long period and affects physical, emotional, intellectual, social, or spiritual functioning" (p.336). According to Austin (1998), there are two criteria, duration of the condition (expected to last more than 3 months) and impact on the child's functioning (one that limits a child's functioning or leads to needing medical attention beyond what is normally expected for a peer. Hayes' (1997) definition of chronic illness is "one that is not only long term, but is either not curable or has residual features that result in limitations requiring special assistance or adaptation in function" (p.261). Clearly these definitions pertain to many childhood psychiatric

illnesses but very few parenting studies include them. This section discusses parenting studies of children with a variety of physical illnesses.

Mothers and fathers respond differently to having a child with a chronic illness. Knafl and Zoellers' (2000) descriptive, cross sectional study found that parents in the same family have varying views in general, but there was an 80% agreement that the illness is in the foreground of the family's lives. Fathers lacked perceived competence in illness management, which the researchers attributed to the fathers' belief that they had less or no responsibility in these tasks. Most parents were likely to minimize the severity of illness, but the mothers were more likely to emphasize the impact of the illness. An interesting finding in this study was that the small cohort of mothers whose partners refused to participate reported a much less positive experience. The study is limited therefore in that the negative impact may have been mediated because the majority of participants were more likely to be parents with supportive communication patterns.

Using the Hymovich Parent Perception Inventory, Heamann (1995) compared perceived stressors and coping strategies of mothers and fathers of 133 children who had developmental disabilities. Significant differences were found between women and men in perception of four stressors; mothers were more stressed by having to find the right agencies to help their child, and felt more "worn out", whereas fathers were more stressed over the child's health, sexual relationships with the spouse, and health insurance. Notably, the child's future was the predominant concern for both parents. The data in this study relied on self-reported questionnaires and generalizability was limited by lack of diversity in the sample. Additionally, cross sectional data may not reliably measure a process such as problem focused coping strategies.

A phenomenological study conducted by Glasscock (2000) described the lived experience of being a mother of a child with cerebral palsy in a convenience sample of 15

mothers recruited from neurology clinics. Four themes emerged: caregiver burden, family and social support, women's roles, and socioeconomic issues. The alteration and demands on the role of the mother was powerfully expressed and evident but no mention was made of the father's contribution. Although Glasscock (2000) described the method of phenomenology and the transcription analysis process, the themes identified seem simplistic when compared to the meaningful quotes selected for the report. Mothers talked of "breaking points" (p. 409), "not leaving their child for anybody, for anything" (p.409), "when you have special needs kids it's very hard to do things with friends" (p.410), and "I'm going to be there...but I can't leave her" (p.410). The mothers' words spoke more eloquently of the depth of their experience than the reported themes implied.

More paradoxical themes emerged in Kearney and Griffins' (2000) phenomenological study of parents' experiences with young developmentally disabled children. The parents spoke of hope, love, strength, and joy, along with anguish and sorrow, thematically interpreted by the researchers as: joy and sorrow, hope and no hope, and defiance and despair. The authors discussed the prevailing assumption of society that this would undoubtedly be a tragic parenting situation and also noted professionals' concerns that the parents are in denial of reality. Kearney and Griffin's (2000) study presented some alternative interpretations of a non normative parenting experience.

Fathers are a neglected area of parenting related research (Whyte, 1997). Recognizing this, Katz and Krulik (1999) conducted a quantitative study of 80 fathers, some with children with chronic physical illness, and some with healthy children. The researchers looked at the level of stressful life events, self-esteem, social support, marital satisfaction, and involvement in the care of the child. Significant differences were found in that fathers with children with chronic illnesses experienced a greater number of stressful life events and expressed feelings of low self-esteem

compared to fathers with healthy children. No significant difference was found on social support and marital satisfaction. Katz & Krulik's (1999) study was with rural Appalachian families limiting generalization. However, marital satisfaction was also not found to be a significant problem in an analysis of The National Study of Families and Household national data set to ascertain the impact of childhood chronic illness on the family (Eddy & Walker, 1999).

Differing family management styles have been found in family response to chronic physical illness in their child. Using triangulation methodology, Knafl, Breitmayer, Gallo, and Zoeller (1996) studied 63 families for management styles using structured and semi structured data collection techniques. They found five styles, thriving, accommodating, enduring, struggling, and floundering. This research provided an important basis for interventions tailored to family management styles but needs to be replicated among a larger array of illness situations including psychiatric illness.

A common thread running through the studies is that parenting a child with a chronic illness involves learning to navigate and struggle with the system, which can involve health providers, insurance, government and education. Dixon (1996) reminds us that the historical view of parent provider relationships is out of date because most chronically ill children are now being cared for in the community and many of the foundational studies were on hospitalized children. The themes identified by her overview of the new research base on relationships between parents and health care providers included issues with trust, information gathering, participation in care, and decision-making.

With regard to parent /provider relationships Kirschbaum and Knafl (1996) compared two qualitative studies, a grounded theory study of parents whose child had a chronic illness (diabetes) and a phenomenological study of parents with a child with life threatening illness (non specified). Major themes emerged of trust, expectations, decision-making, and need for

information. Parents differed in their preferred style of communication with health care providers; some parents favored being the main decision-makers and others to negotiate with authority figures. This qualitative evidence supports other research that indicates some families want more dependence and others more independence in child health care. It also supported the conclusion that parents have conditions for establishing trust, as postulated by Thorne and Robinson's (1989) guarded alliance theory. This theory was developed as a result of studying the process of parents developing trust in health care providers in a neonatal intensive care unit. Holaday (1997) stresses that more research is needed that focuses on the interaction between the microsystem (the parents' internal coping mechanisms), and the macrosystem (the primary health care providers and economic systems).

Nursing is part of the macrosystem but there are few nursing intervention studies. Whyte, et al (1998) conducted a study on the clinical effectiveness of family community nursing. The researchers identified the method as action research using self-reflective enquiry and semi-structured interviews. The sample consisted of twenty-six families; in all but two it was the mother who was interviewed. The families were asked whether the service they received included the family as a unit or focused on the child; the answers were evenly divided. The study identified the whole family's need for information, as well as the need for nurses to listen to other family members. The study is limited because there is not enough data available regarding the perspectives of other parental figures to be able to understand the extent to which this influences clinical effectiveness. For example, in practice the nursing team usually intervenes with the primary care-givers or whoever is there when they visit; as this is during the day it usually excludes the father and often the siblings who are at work or at school. In addition the study did not include families of a child with psychiatric illness.

Families do not easily discuss psychiatric health issues. This was revealed in an ethnographic study conducted by Denham (1999) with multiple members of eight families in rural Appalachian communities. However, the findings should not be generalized to other populations without further study. Whyte, Baggaley, and Rutter (1995) concluded that we need more studies about the differences and commonalities in parenting a child with any type of illness. Children with chronic physical illness have an increase in behavior problems and there is an association between chronic ill health and disturbed psychiatric health (Whyte, 1997). However, very few studies were found that looked at differences and similarities when a child has a chronic physical illness compared to a child with a chronic psychiatric illness. Also, very few studies related to parenting a child with a chronically ill child include those with a psychiatric illness, although these families experience many of the same stressors and problems.

Societal and historical forces have significantly impacted families with a child who has psychiatric illness. In the last half of the 20th Century significant progress was made in use of psychotropic medication and understanding of the biological basis of psychiatric illness, but families still face issues with stigma (Howard, 1994). The majority of studies to date on parenting a child with a psychiatric illness have been done with offspring that have reached adulthood. The next section discusses these studies.

Parenting an Adult Child with a Psychiatric Illness

Parenting research in psychiatric illness has primarily been done on the adult child. Familiar themes seen across studies are living with sorrow, anguish, and constant worry, living with guilt and shame, issues with health care provider relationships, comfort and hardships, coming to terms with difficulties, and hoping for a better life for the child (Cooke, Cohler, Pickett & Beeler, 1997; Eakes, 1995; Hobbs, 1997; Howard, 1994).

Pejlert (2001) used a phenomenological perspective to study the meaning of being a parent of an adult son or daughter with severe psychiatric illness living in institutional and sheltered care settings. The findings revealed ongoing grief and loss, defined by the researcher as chronic sorrow. Parental caregiving emerged as a lifelong effort and stigma was an overarching experience. In their dealings with the care system, parents reported that relationships were unpredictable, some causing conflict and others giving comfort. A strength of this study was that fathers were equally represented in the joint interviews. However, the author noted that the couples might have felt more free to talk if interviewed separately. Pejlert's (2001) thematic analysis is clearly described in the report with plausible interpretation. However, it is limited in that the amount of parenting contact with their children was inconsistent, ranging from in person daily to telephone only, and as it was conducted in Sweden the study may not be pertinent to the USA. The findings however mirrored other study results with regard to the concepts of grief and loss (Clubb, 1991; Eakes, 1995; Howard, 1998; Tuck, duMont, Evans & Shupe, 1997).

In a study of 15 caregivers of adult psychiatric patients, Rose (1997) used a qualitative approach framed in symbolic interactionism to interpret the perception of social support for the caregivers. Findings showed that caregivers might have difficulty getting support because of stigma attached to a psychiatric diagnosis and lack of understanding of its cause, treatment, and prognosis. The caregivers in this study expressed a strong desire for affirmation, stronger than the desire for information. They also perceived a lack of professional support when health care professionals did not acknowledge the families' perspective.

Little is known about family response to psychiatric illness over time and there are few nursing studies that describe stress in families with psychiatric illness when compared with studies of other illnesses. Rose, Mallinson, and Walton-Moss (2002) conducted a grounded theory study to describe the family's responses to severe psychiatric illness. There were 29

participants, representing 17 families who were interviewed three times over two years. The relatives' diagnoses were Schizophrenia, Major Depression, and Bipolar Disorder, with a sample criterion of at least two hospitalizations. The age of the affected family member was not identified in the report; over half were still living with their families. Using the constant comparison method of analysis the "ambiguity of living with psychiatric illness" emerged as the central concept. Additional findings in Rose et al.'s (2002) study were that families had goals of pursuing normalcy, confronting ambiguity, and seeking control over the illness. The families stories supported findings in other studies that demonstrated the difficult process of accepting the social implications of psychiatric illness. The strength of this study was that it allowed for a strong description of the process of family response to psychiatric illness over time. Notably, the same pursuit of normalcy was seen in studies with parents of children with chronic physical illness (Norbeck et al, 1991).

A similar grounded theory study was conducted by Badger (1996) about family members' experiences of living with relatives who were diagnosed with depression. Interviews with family members revealed a core category of "family transformations" in three stages: acknowledging the strangers within, fighting the battle, and gaining a new perspective. The first stage involved finding socially acceptable explanations and living two lives to cope with the stigma. The second was described as alternating strategies of "holding our ground" (analyzed by the researchers as protective) and "moving forward" (analyzed as coercive) (p.24). The final stage, "gaining a new perspective", included "protecting oneself" and "becoming hopeful" (p.25).

Similar issues surrounding parent /health provider relationships are prominent when the child has a psychiatric illness as with parenting a physically ill child. Studies suggest that parents of psychiatrically ill offspring perceive health care professionals as not caring and they call for concerned and collaborative care (Howard, 1994; Rose, 1996; Rose, 1998; Stubblefield &

Murray, 1999). Very few studies in the aforementioned meta-analyses included children with psychiatric illness and none with Bipolar Disorders. This is significant because, according to Patterson and Blum (1996), health conditions that are invisible and include the ebb and flow of uncertainty, present the greatest emotional risk to families. The next section discusses the experience of parents of young children with "invisible" disorders.

Parenting a School Age Child or Adolescent with a Psychiatric Illness

The definition in law of a disabled child includes serious emotional disturbance. However, most nursing studies of families with disabled children do not include children with psychiatric illness although they face the same kinds of burden of care as families with children with physical disabilities (Cook et al, 1997). A trend in studies is to either refer to psychiatric disability as primarily those with pervasive developmental disabilities, or to exclude those with behavioral or emotional disabilities. It is well known that, apart from some short situational depressions, psychiatric illness in children is usually not a short-term condition (Birmaher, et al 1996). Recognizing this, the Special Education accommodations may include nursing care as necessary in order to provide for a least restrictive educational environment for an emotionally disabled child (Individuals with Disabilities Education Act, 1997).

Parents are a crucial component in the quality of an individual's response to treatment. Psychiatric studies have demonstrated that levels of relatives' distress, their coping strategies, and what they perceive as the cause of the illness, are associated with improvement or deterioration of symptoms in mentally ill individuals. There are heavy responsibilities placed on parents in home management of the child's behaviors and treatment adherence. Studies suggest that community based as opposed to hospital based psychological interventions for school age children referred for treatment are most effective (Birmaher et al., 1996; Burns et al., 1995; Carr, 2001; Geller &

Luby, 1997). Parent training is focused on helping parents develop skills to monitor specific behaviors, identify antecedents of unwanted behavior, and monitor stimulus and contingency techniques. This is a taxing regime of treatment for families already dealing with difficult psychosocial demands (Carr, 2001).

Using a qualitative design Delaney and Engles-Scianna (1996) explored "how parents define their child's emotional illness and psychiatric treatment needs" (p.15). Four themes, well supported by participant quotes, emerged from the study. First, parents defined the dilemma of securing services for the extremely serious and difficult behaviors often occurring over years rather than months. Another theme was the parents' struggle to understand the child's illness when having to integrate differing professional opinions. The third and fourth themes centered on securing a future for their child and their family. This study used a semi structured interview with 19 parents of children aged 3-13 who required hospitalization for intensive treatment for disorders ranging from depression, Attention Deficit Hyperactivity Disorder (ADHD), Post Traumatic Stress Disorder (PTSD), Obsessive-compulsive Disorder, and Intermittent Explosive Disorder.

The profoundly disturbing stories in Delaney and Engles-Scianna's (1996) study exposed a severe shortfall in care and support for families of children with behavioral and emotional difficulties. Extended dialogues in this study illuminated parent's skepticism about psychiatric health professionals. Although the authors did not explicitly name their method of qualitative study the implication is that it is grounded theory, as a constant comparative method using codes and memoing was used for data analysis. The methodology is sparsely described, which makes replication difficult. A strength of the study is that in some instances both mother and other parental figures were interviewed.

Family relationships with professionals have often left parents of younger children feeling blamed, discounted, or frustrated (Carr, 2001; Delaney & Engles-Scianna, 1996; Faux, Siedermann, &Young, 1996; Scharer, 2002). According to Whyte (1997) there is a perceived difference in values and opinions between parents and professionals in relation to psychiatric health care of children and consequently an under use of psychiatric health services. This issue was addressed in a study conducted by Starr, Campbell, & Herrick (2002) who used the Expectations of Psychiatric Health instrument to assess factors affecting use of the psychiatric health system by a broad age range (5-19 years) of children in a rural community. The study examined 30 rural parents' expectations related to psychiatric health treatment, the provider/client/parent relationship, social and cultural factors, and accessibility to psychiatric health services. A limitation of the study is that only dichotomous data is available, however large percentage differences were found. Although 80% felt that psychiatric health professionals were needed for their child and 87% believed that the professionals would find out what was wrong with their child, more than half (63%) were concerned that psychiatric health professionals would not care for their child as a person and 70% were concerned that psychiatric health professionals would not respect their child.

Nevertheless, there is evidence that community based nursing interventions with parents of children with a psychiatric illness are effective. In their study of two interventions Drummond, Fleming, and Kysela (2001) assessed whether nurse instigated treatment can improve parent child relationships in school age children with behavioral disorders. One comparison group pilot study assessed a 6-week home visit parenting educational program. A significant difference was found between the intervention group and the comparison group parents in outcome scores of sensitivity to their child's cues, responsiveness to child distress, social emotional growth fostering, and cognitive growth fostering. The second intervention examined by Drummond, Fleming, and

Kysela (2001) involved a sample of 29 parents. In monthly parent group meetings, and home visitations, nurses provided information, affirmation, and emotional support. The parents in the intervention group were significantly less directive (p= .008) and more responsive (p=. 018) with their child on scores of a frequency of praise measure.

The literature reviewed revealed minimal studies of children's psychiatric health in the elementary school age years and a lack of inclusion of children with psychiatric disorders in family, pediatric chronic illness, and disability studies across disciplines. The next section reviews theoretical perspectives that have been used by in nursing to view both the family and psychiatric disorders.

Theoretical Perspectives on the Family and Psychiatric Illness

The development of family theory required a paradigm shift from looking at the client as an individual to looking at the family as client. Many of the concepts used in family nursing frameworks were borrowed from existing sociological, anthropological, or psychological theories (Mercer, 1989). The main theoretical foundations used in non-normative family transition research and practices are systems, stress, and adaptation theories (Friedmann et al., 2003). From these grand theories, nurse researchers have developed family focused theoretical perspectives, mainly family systems theory, ecological frameworks, and the resiliency model of family stress, adaptation, and coping (Vaughan-Cole, Johnson, Malone, & Walker, 1998).

The current review of literature indicated that there is a good balance of inductive and deductive research approaches for family based research. However, the majority of researchers do not identify or discuss a framework for their studies. Those that did mostly studied stress, adaptation, and coping concepts (Charron-Prochownik, 2002; Clubb, 1991; Donnelly, 1994; Snowden, Cameron, & Dunhan, 1994). Self-efficacy theory has also been used to describe

parents' reactions to the extra demands of a child with special needs (Heamann, 1995; McLenna-Reece, 1998). There is still little evidence of formal middle range family theory that is unique and distinctive to nursing (Whall, & Fawcett, 1990). Psychiatric illness issues have a less thorough inductive research base because the majority of the studies are conducted by medical, psychological, and sociological disciplines using experimental designs. The main outcomes assessed for relatives in these studies include distress, expressed emotion, subjective level of burden, and relatives' coping strategies (Lobban, Barrowclough, & Jones, 2003).

However, there are several theoretical perspectives relevant to the study of parents with a younger child diagnosed with Bipolar Disorder. One of the mid range theories that has been used successfully in parenting studies of children with chronic illness is Mishel's (1997) Uncertainty Model. This concept has proven useful in research on families with a multitude of chronic illnesses and shows great promise in the development of nursing interventions (Dodgson et al, 2000; Garwick, Patterson, Meschke, Bennett & Blum, 2002; Morse & Penrod, 1999; Santacroce, 2001). The uncertainty variable has not yet been tested in parenting children with psychiatric illness. As studies in this population show that ambiguity is an important stressor (Norbeck et al., 1991) it will be helpful to investigate how uncertainty can be identified and addressed for these parents and children.

Nurse researchers are developing new frameworks that show promise for use in chronic psychiatric illness research. Forschuk and Dorsay (1995) recommend an integrated approach using Peplau's interpersonal therapeutic relationship theory and family systems theory. Using a case study approach they demonstrate the use of Peplau's theory in caring for the individual seeking help, integrated with family systems theory that addresses the impact on the family as a whole. There is an increasing evidence of a shift towards a systems and strength and resilience perspective in both research and practice. Feeley and Gottlieb (2000) recommend the use of

McGill's model of nursing to describe how this conceptual shift from a deficits model to a strength perspective can influence how clinicians and researchers view families, and how researchers can focus on positive traits, assets, and capabilities in families. Phenomenological studies can be useful in eliciting the family's negative and positive experiences.

Although nursing has incorporated many aspects of the biomedical model, there are many questions about its effectiveness. Hall (1996) critiques use of the model in psychiatric nursing practice, suggesting that its narrow focus dehumanizes the patient by forcing the social, economic, and cultural factors that influence a person or family's life into the background. She feels that research that flows from this perspective does not include the richness of individual experience or the positive effects of a person's behaviors thus adding to stigma, stereotyping, and humiliation. Hall's (1996) thoughtful critique calls for a conceptual framework that embraces the patient holistically, looking beyond labels and multivariate concepts, one that clarifies the right of nurses to advocate for their clients and encourages nurses to identify their biases.

Qualitative methods may reveal important areas hitherto overlooked in previous quantitative studies. Important differences were found in Carey, Nicholson, and Fox's (2002) mixed method study comparing parenting practices in mothers of healthy children with mothers of children with congenital heart problems. Findings in self report and observational designs showed no significant differences between the two groups whereas the qualitative results revealed very high levels of vigilance in the mothers of the sick children.

For the current study the researcher chose to use a phenomenological method that does not use a preselected theoretical framework. Applying positivistic scientific methods may not allow for the participants' perception of reality to emerge. Stubblefield and Murray (2002) propose that descriptive phenomenology, incorporating bracketing and participant validation, is appropriate and valuable for psychiatric nursing research because it allows for description of the

unique nature of the clients' realities. Although the discussion in the article is primarily related to the experience of being mentally ill the researcher proposes that Stubblefield and Murray's (2002) arguments are equally relevant to the parents of children who have a Bipolar Disorder. The phenomenological methodology and method chosen for this study is described further in Chapter Three.

Summary

Overall, the literature review revealed that parenting a child with a psychiatric illness could have both positive and negative dimensions. The major aspects reported were burden, stress, problems with trust and relationships with health care professionals, different roles, coping and management styles, sorrow and worry, societal stigma, and an expressed need for information. Family disequilibrium is usually present and the illness is always in the foreground for these parents.

Qualitative studies have provided a sound base in the study of parents with children with physical chronic illness and there is a substantial body of literature in the area of family centered care. Nevertheless, there is a paucity of conceptual and empirical information about the effects of a psychiatric illness during the elementary school age years. It is vital that nurses better understand what families wish from the health care provider, what processes occur in the family over time, and the differences and similarities in children of varying ages and illness. For example, are the skills that we have developed for the care of families with adult offspring with schizophrenia, or adolescents with depression and suicidal tendencies transferable to those with younger children with the same or different disorder? We need to know if parents feel affirmation from caring for psychiatrically ill children in the same way as parents of children with physical disabilities. Therefore, families with children with psychiatric illness need to be included in the

chronic illness research. Neglecting to include these children reinforces the schism between psychiatric and physical illness.

Nursing studies have put a greater emphasis on organic deviations from health although it is well known that behavioral and psychosocial problems put children at greater risk for both illness and risky behaviors. The perspective in this study is that knowledge related to the parenting experience when a child has Bipolar Disorder will add to the knowledge in family related chronic illness research. To date few studies have examined the meaning of having a child with a psychiatric illness to parents, especially to those with younger age children. These parents may be more difficult to involve in research because their stigmatized status makes them more vulnerable to harm. Hence, a promising area of research is a qualitative approach that investigates the parents' perceptions of the psychiatric illness experience and meaning by providing an opportunity for parents to talk freely about their experience. The following chapter discusses the methodology and method used in this study to address some of the deficiencies found in the literature review.

CHAPTER III

METHODOLOGY, METHOD, AND DESIGN

Introduction

The purpose of this study was to explore the meaning of parenting a child who has been diagnosed with a Bipolar Disorder. This study describes the parenting experience in terms of a thematic analysis of the meaning and essence. This chapter describes the researcher's rationale for use of a descriptive existential phenomenological method to guide the study and the underlying philosophy of the methodology. In addition, it also discusses the design of the study, role of the researcher, data collection, interpretation processes, and issues of validity.

Evolution of the Existential Phenomenological Approach

Epistemological questions concern what can be known, who can be the knower, and can subjective truth be thought of as knowledge? Differing philosophical perspectives dictate by what criterion beliefs can be measured and what constitutes the authority against which truth can be measured (Campbell & Bunting, 1999). To Cartesian thinkers the thinking mind is separate from direct contact with the world, the mind and the body are separate, and there is no meaning unless the statement is verifiable. This is contrary to phenomenological thought where the knower and the known cannot be separated (Pollio, Henley, & Thompson, 1997).

The worldview of phenomenology accepts that truth can be revealed through the words of those that live the experience and describe the essence of that lived experience (Thomas & Pollio, 2002). During the 18th century and particularly in the 19th century there was a movement towards existentialism as a revolt against the logical positivists' viewpoint that the universe is a closed system. The qualitative existentialist movement centered on the proposition that existence

cannot be exhaustively described in scientific terms, and stressed the uniqueness of the individual.

Existentialism originated in nineteenth century Denmark, with Soren Kierkegaard, who first used the word "existence" with the philosophical connotation that it has today (Wahl, 1965). Sartre (1965), a twentieth century philosopher and political analyst, defined existentialism as "a doctrine which makes human life possible and in addition, declares that every truth, every action, implies a human setting and human objectivity" (Sartre, 1965, p.32). As defined by Thomas and Pollio (2002) "existentialism is a philosophy about who we are and how we may come to live an authentic life" (p.9).

The history of phenomenology is directly connected to the 18th and 19th century thinkers that set out to find a systematic way to examine new and old questions about the nature of human existence and experience. They asked is duality real, or is there oneness. One of these philosophers was Edmund Husserl (1964/1999) who first used the term phenomenology. He believed that the fabric of existence is experience, which, to him, has universal dimensions. Husserl (1964/1999) introduced the idea of "seeing" while holding one's own experiences in abeyance. He wrote that cognition "is more easily conceivable, at least for anyone who can assume the position that pure "seeing" can hold all natural prejudices at arms length" (p.252). Husserl was particularly concerned with the essence of consciousness and the return to things that happen on a day-to-day basis (Thomas & Pollio, 2002).

Heidegger, a student of Husserl, has been of particular importance in the development of phenomenological thought (Thomas & Pollio, 2002). Heidegger (1949) moved the central focus towards ontology (a science based on being or existing). To Heidegger, what it means "to be" is the central question. For phenomenologists "being in the world" refers to the belief that human beings and environment are inextricably intertwined, person and world co constitute one another,

and one has no meaning if independent of the other. One cannot fully understand one without the other for they are two sides of the same coin (Valle & Mohs, 1998). In a similar context Heidegger (1949) also expressed the concept that "being" is the figure against which we are grounded "in the world." Thus, in the human experience some things stand out (figural) but only have meaning within the context of the four major grounds of existential human existence, time, body, others, and the world (Thomas & Pollio, 2002). These can also be described as temporal, corporeal, relational, and spatial life worlds (Munhall, 1994).

Heidegger is classified as existentialist because he looks into the uniqueness of the individual person living in the world (Munhall, 1994). In his words "the question of existence never gets straightened out except through existence itself. The understanding of oneself which leads *along this way* we call *"existentiell"* (his italics) (Heidegger, 1962/1999, p.275). According to Welch (1999) for most existentialists one comes to understand humans through the analysis of critically difficult situations such as that described in the proposed study.

Phenomenology: General Perspective

In contemporary philosophy phenomenology is not a school of thought but rather a movement with various meanings for different people (Welch, 1999). Three movements developed in the 20th century, the Duquesne school which followed Husserlian (descriptive) thought, the Dutch school (a combination of Husserlian and the interpretive hermeneutics of Heidegger), and the Heideggerian (interpretive) school (Thomas & Pollio, 2002).

One of the founders of modern phenomenological thought is Merleau-Ponty (1908-1961). In his words (1962/2000, p. 79) phenomenology "offers an account of space, time, and the world as we live them. It tries to give a direct description of our experience as it is without taking into account a psychological origin and the causal explanations." In his doctoral thesis "The

Phenomenology of Perception" (1962/2000) he developed a detailed case for considering the importance of an individual's experience, "I am the absolute source, my existence does not stem from any antecedents from my physical and social environment, instead it moves towards them and sustains them, for I alone bring into being for myself the traditions that I elect to carry on" (p.80); a rejection of the positivistic view of science.

In 1941, Sartre and Merleau-Ponty were part of the same French resistance group and they published a journal together after World War II. However, Merleau-Ponty moved away from complete agreement with his friend believing that Sartre continued to have dualistic thinking (Rabil, 1967). Merleau-Ponty combined many of Sartre and Heidegger's existential thoughts with Husserl's transcendental approach. His main argument was that the body itself is a knowing subject, maintaining that consciousness is always embodied. Merleau-Ponty (1962/2000) sought to remind us of the insoluble link between consciousness, meaning, and the world, "because we are in the world we are condemned to meaning" (p.90). Another important concept is rationality, which unites subjectivism and objectivism "to say that there exists rationality is to say that perspectives blend, perceptions confirm each other, a meaning emerges" (p.90).

Merleau Ponty's (1962/2000) ideas continued to evolve over his lifetime and are incorporated into phenomenological research today. The primary ideas are embodiment, as discussed previously, the primacy of perception, functioning intentionality, and the need to focus on the lived experience. The concept that has primacy in Merleau–Ponty's (1962/2000) philosophy is perception, which he defines as "the background from which all acts stands out and is presupposed by them, (p.82)". He states, "We must not, therefore, wonder whether we really perceive a world we must instead say the world is what we perceive" (p.87). Existential phenomenologists are also concerned with functioning intentionality, which refers to the way humans are directed towards what we feel connected to in an embodied form (Thomas & Pollio,

2002). Intentionality is "to take in the total intention-not only what these things are for representation (the properties of the things perceived, the historical facts, the ideas produced by a doctrine" (Merleau-Ponty 1962/2000, p.89).

The phenomenological approach is compatible with nursing's values and philosophical foundations and has been used as a valid nursing research approach since the 1970's. Nursing pioneers, who included Rosemary Parse, Carolyn Oiler, and Anna Omery, investigated the congruency of phenomenology with nursing practice and research and its concern with the wholeness and patterns seen in human experience (Thomas & Pollio, 2002). More recently nurses have found inspiration from these early nurse thinkers, as they appraise the unique methods needed to investigate the art of nursing as differentiated from the social sciences (Porter, 1998).

The Thomas and Pollio (2002) method used in this study is in accordance with Merleau–Ponty's philosophy because of his conceptualization of embodiment, culture and holism. Thomas and Pollio's (2002) method enabled understanding of the meaning of the parents' experience through dialogue with the participants and interpretation of their words.

Overview of the Methodology of Phenomenology

Bracketing

One of the central concepts in using phenomenology as a method is that of recognizing one's own preconceptions and experiences in order to separate them from the participants and hold them in abeyance. This process, termed bracketing, acknowledges the space that we are in, the time we are in, our past, present, and future, the body that enables us to be in the world, and where and when we are interpersonally connected (Munhall, 1994, p.55). Phenomenologists believe it is essential to see the lived experience of research participants, as they are, not filtered

by previous knowledge, values, and beliefs. The researcher is on par with the participants, and communicates receptivity, a willingness to be taught by participants, and openness to feedback (Thomas, & Pollio, 2002).

Reflection

Reflection on the words of the participant is of particular importance in the phenomenological process. "The phenomenologist borrows the description of the participants experience and reflects on them" (Munhall, 1994, p. 304). The subjective experience of the individual or group is valued and described; linguistic, social, and cultural consideration help imbue the experience with meaning. According to Merleau Ponty (1962/2000) it is only through our personal experience and consciousness that language comes to have any meaning at all.

Intuition

In the analysis of the participant's words and through noted observations of body language and tone and pitch of voice the researcher is required to use a certain amount of intuition. Intuitiveness involves reflection and permits the researcher to discover meaning (Lethbridge, 1991). Conducting research while being consciously aware of our intuitive process requires purposeful, compassionate listening. Intuitive inquiry positions the participant's experience at the center of the inquiry and stays as close to the voice of the persons as possible (Braud & Anderson, 1998).

Description

The purpose of a phenomenological study is to describe experience as it really is without considering causation. "The aim of description is to give an account of all the pertinent facts; it cannot be an account of all the facts because the facts are infinite in number" (Farber, 1966, cited in Munhall & Boyd, 1993, p.101).

Rationale for Use of Phenomenology

The researcher's rationale for choosing the phenomenological method for this study is that it is congruent with her worldview, a belief in holism that questions whether an individual and their world can be fully known through breaking into separate parts. With phenomenology individual uniqueness is valued, and each person's experience is his own reality. The researcher's position is that an individual can interpret their own experiences and give meaning to them so that new understandings and insights may emerge. Bracketing helps the researcher to understand their own experiences, values, and prejudices, in order to be temporarily emancipated from preconceptions. In the words of Merleau Ponty (1962/2000) "in order to see the world and grasp it as paradoxical we must break with our familiar acceptance of it" (p.85).

Rich human experience can be lost in quantitative studies. The experimental approach presumes the presence of a causal relationship through the objectification of the subjects. For many nurses, including the researcher, this leaves out other modes of awareness and experience such as intuition, empathy, feelings, and intentions. Existential phenomenology does not attempt to explain or predict but to see the world with eyes open with awe and wonder (Thomas & Pollio, 2002).

The phenomenological search for meaning may increase the nurse's understanding of their client's feelings. Parents dealing daily with the challenging role of parenting a psychiatrically ill child are already stressed and hurting, which also added rationale to my reasons for choosing a method that becomes a caring act (Munhall, 1994). In addition, there has been very little study of the experience of parenting a child in their middle years with a mood related disorder, making a phenomenological baseline critical to developing nursing knowledge.

The Method of Phenomenology: Applied

The purpose of the study was to describe the lived experience of parents of school age children who have been diagnosed with Bipolar Disorder. The phenomenological perspective helps us look at ordinary daily human life experiences in context in order to discover meanings. The existential phenomenological approach developed by Pollio et al (1997) and further developed by Thomas & Pollio, (2002) was chosen as the applied method. This method advocates that the researcher gains a strong theoretical perspective and knowledge base through study of pertinent literature and remains true to the philosophical worldview of Merleau-Ponty described earlier in this chapter. The method adheres to the principles of bracketing, personal interviewing, hermeneutic part to whole analysis, and development of thematic structure in the context of an interdisciplinary study group. The participant remains the main focus, themes are returned to participant representatives for validation, and the report is disseminated in publications and presentations (Thomas & Pollio, 2002).

Characteristics of Sample and Selection Process

The sample for the study was purposefully chosen because it was essential that the participants had personal experience of being a parent of a child with a Bipolar Disorder. Potential participants were recruited through networking, and by placing flyers in Mental and Pediatric Health Departments and offices, in three major cities in the Southeastern United States. The flyers identified the purpose of the study and the inclusion and exclusion criteria. Additionally, potential participants were invited to join the study through information provided to support groups and participant referral. A telephone number was provided in the flyer for interested people to call about the research.

Recruitment for the study proved more of a challenge than anticipated. Three hundred flyers and brochures describing the study and inviting participation were mailed to psychiatric

health and pediatric professionals and posted in buildings that families frequented. In addition, the researcher met with many professionals personally to present the study including psychiatrists, counselors, Department of Human Resources staff, school counselors, and school nurses. Three participants were recruited through information given to them by mental health professionals, and one responded to a flyer at a pediatric clinic. The remainder contacted the researcher after announcements were made in various support groups.

After the potential participant contacted the researcher the interview was set up at a private setting convenient to the participant. All but three chose to be interviewed in their own home; two were interviewed in a private room at the researcher's university, and one in an office at the child's school, which was facilitated by a school nurse . All participants expressed gratitude for the study remarking that the unstructured nature of the interview was helpful. Without exception the participants were eager to talk and required no prompting. No time limits were imposed. The interviews continued until every participant felt that they had exhausted their descriptions. The interviews were an intense experience for both researcher and parent because of the content and a great need to tell their stories. At the close of the interview the participants were given information on local and national resources. The children were not present during the interviews.

Self as Instrument

The researcher collected data in face-to-face personal interviews and served as the primary instrument through which data was collected by actively seeking a dialogue with the participant. She was not available for clinical consultation but was prepared to refer participants to appropriate health care providers, other resources, and support groups when needed. Intervention was considered inappropriate unless a clearly dangerous situation was present. The

rationale for intervention in crisis situation is that the nursing advocacy role is more imperative than that of research.

Authenticity was enhanced by the researcher's ability to use personal history to respond to another person. Genuine caring reflects authenticity. As she shared concern about families with psychiatric illness the researcher acknowledged her own experience, and used her personal history as a motivation to study and understand as suggested by Pew, Bechtel, and Sapp (1999). In accordance with Braud and Andersons' (1998) suggestions for performing phenomenological inquiry the researcher endeavored to pull together her reactions, imagery, thoughts, feelings, emotions, intuitions and sensations and gain a sense of being in the moment with the participant.

Data Collection and Recording

The participants were provided with an information sheet describing background information, the study's purpose, protection of confidentiality, the investigator's role and qualifications, and the method and procedures. The study was described during the initial telephone contact and in the recruitment flyer. At the interview appointment the participants signed a consent form (*See Appendix A*) after all of their questions were addressed and a signed copy left with the participant. The equipment used for the interview was a tape recorder. The interview was audio taped and the narratives transcribed verbatim because every word is important and needed to capture the exact words of the participants. Names and references to places were removed and pseudonyms used instead. The researcher was the only interviewer and transcribed most of the interviews; the remainder were transcribed by a professional transcriptionist, who signed a confidentiality pledge (*See Appendix C*).

The specific opening question was "When you think about your life with your child what kinds of things stand out for you?" Demographic information on age of participant, age of child, ethnicity, gender, relationship to child, medications, employment, and family history was

collected prior to the interview. The interview was continued until the participant felt like they had sufficiently described their experience to their own satisfaction. The average length of time for the interviews was two hours with the longest over three hours and the shortest one and a half hours. Altogether, 19 hours of narrative was transcribed. Participants were advised that they could stop the interview at any time. Additional participants were interviewed until no new information became available and a saturation point was reached. Ten participants were interviewed for this study. A meticulous research log was maintained in which the researcher described contextual details such as physical setting, non-verbal communication, linguistics, disruptions, and subjective observations.

Pilot Study

A pilot study was conducted with a parent of an adolescent with the diagnosis of Bipolar Disorder to test the question and the equipment. The narrative for this interview was analyzed by the researcher and members of an interdisciplinary phenomenological interpretive group that meets weekly at the University of Tennessee, Knoxville. No change was made in the original question.

Bracketing

Prior to the interviews, bracketing to highlight the researcher's presuppositions and prejudices was done. The bracketing interview was conducted by a researcher with experience in phenomenology using the same question and analyzed by the interpretive group. The researcher identified that the experience of being a parent of an adult child who is diagnosed with a mood disorder remained very close and intense. The analysis in group and consequent self reflection was a very useful experience. The major themes identified in the researcher's experience were feeling like she was in a war situation, waiting for another crisis to happen, fighting the healthcare and educational system, anger, loneliness, and emotional anguish. By recognizing her personal

preconceptions, beliefs, and values the researcher was cognizant of making a sincere effort to hold them in abeyance as she conducted and analyzed the interviews.

Data Analysis

Using the method described by Pollio et al (1997) and Thomas & Pollio (2002) the interviews were transcribed and read in the order in which they were collected. Transcripts were read from the parts to the whole, with line-by-line analysis and interpreted by the researcher, who spent time reflecting and listening to the audiotapes to intensify the sense of the tone and nuance of the descriptions. Three transcripts were analyzed by the interdisciplinary phenomenological group at the University of Tennessee. The group signed a confidentiality pledge (*See Appendix B*) and the researcher took notes during the group analysis. Hermeneutic analysis of each individual transcript was performed to yield commonalities in meanings, situations, and life experiences. Analysis was further divided into themes and depiction of exemplars and paradigm cases to clarify the complexities of the parenting experience. This was integrated into a representative thematic structure of the parenting experience. During the analysis portion of this study emerging themes were mailed to all participants who were invited to reflect on them and comment via telephone or by mail in the enclosed stamped addressed envelope. Six participants responded and the thematic structure was reassessed when necessary.

Validity, Rigor, and Reliability

Although qualitative methodologies are alert to the possibility of error they do not purport to achieve statistical reliability or generalizability typical of quantitative research. The perspective taken for this study is "validity means whether one has investigated what one wishes to investigate" (Thomas & Pollio, p.40). Empirical validation in intuitive inquiry relies on the principle of sympathetic resonance. That is, validity is found through consensus building, noting consonance, dissonance, or neutrality, subgroup by subgroup within and across cultures (Braud &

Anderson, 1998). Returning to discuss the results with the participant, which is respectful and increases plausibility, also enhances validation. "Validation in phenomenological studies is just that; the unaltered faithful telling of experiences by people" (Munhall, 1984, p. 84). In considering the volunteer status of the participants, it is acknowledged that the results will be biased towards their experience and that of others may be different. Pragmatic validity will be enhanced if the quotes chosen for the report lead clinicians to take action.

Additional methodological concerns in phenomenological analysis include rigor and appropriateness (Thomas & Pollio, 2002), which was addressed by adherence to the research method and plan and use of interdisciplinary authentication. The researcher deemed it appropriate to choose the method of existential phenomenology, which honors the participants' words and strictly adheres to confidentiality, in order to study the parents' experiences.

Rigor in the study was enhanced by the researcher paying attention to the criteria suggested by Munhall (1994). These are resonancy (do the findings prompt familiar feelings), representativeness, recognizability, relevance, revelations, raised consciousness (seen through a fresh perspective), readability, and responsibility (ethical concerns). With regard to reliability, Thomas and Pollio (2002) state "a concise test of any study is its relevance and value in bringing about new insights regarding the phenomenon being studied" (p. 40).

The degree to which the evidence is credible is influenced by experiential concerns including plausibility and illumination (Thomas & Pollio, 2002). Peer review and participant checks were done to increase the plausibility and credibility of the findings. Sensitivity of the study was addressed by the researcher recording biases, feelings, thoughts, feelings, and historical circumstances in a journal (Pew, et al., 1999). Therefore, in this phenomenological study the combination of methodological and experiential awareness gave an overall measure of credibility,

rigor, and validity (Thomas & Pollio, 2002) which was enhanced by new insights as discussed in Chapters IV and V.

Protection of Human Subjects

The prospective study was reviewed and approved by the University of Tennessee in Knoxville (UTK) College of Nursing Human Subjects Review Committee, and the UTK Institutional Review Board (IRB). The study was thoroughly described to potential participants and mental health or other professionals who might come into contact with the participants. In addition, a presentation on the purpose, method, and background was made to health care professionals at a Psychiatric health Center.

The voluntary nature of the study was explained and participants were given the opportunity to decline or terminate after the interview had started. Written informed consent containing contact numbers for the researcher for potential questions (*See Appendix A*) was obtained and a copy left with the participants. Confidentiality was maintained. No one but the researcher has access to the names and addresses of the participants. Access to the typed transcripts was limited to the principal researcher, the transcriptionist, and the researcher's Dissertation Committee. Identifying information was removed from the transcripts. All materials were kept in a locked file cabinet at the researcher's home and the tapes were destroyed after transcription. Consent forms were stored in a safe place at the University of Tennessee, Knoxville, College of Nursing. The assumption of the study was that the research subjects were coauthors of their own experience, therefore proper reverence was given to the reality of the descriptions.

Risks and Benefits

There were minimal risks to the participants. During the interview some of the participants became emotionally upset while talking about their experiences. The researcher has

extensive experience in talking with parents and was sensitive to any emotional or physical distress. The researcher remained with the participants until they felt that they were ready for the researcher to leave. There was no other form of intervention provided by the investigator. If the participants became acutely distressed the researcher was prepared to transport them to a health professional of their choice or the nearest emergency department. The participant was informed in the consent form that they would be responsible for professional fees before transport. A list of agencies available for counseling was provided to the parents, along with a list of support groups and other resources for families of psychiatrically ill children. Also the participants were encouraged to contact the researcher with any further questions or comments at the telephone contact number provided.

A strength of this design is that there is evidence that sharing personal experiences, especially those previously unvoiced is beneficial to psychological health and well being (Streubert & Carpenter, 1999). The researcher was cognizant of hearing and honoring what may be the previously unempowered voice of the participant.

Summary

Phenomenological studies look for the meaning of the experience for the participant. By using the phenomenological method of inquiry as described by Thomas and Pollio (2002) it is the researcher's belief that increased understanding of what it means to parent a child with a Bipolar Disorder emerged in this study. This description was derived from the parent's own experiences and their own words. The outcome was that the researcher captured the phenomena by uncovering central themes that answered the question of what is it like to parent children with a Bipolar Disorder. This chapter described the philosophical background and method of existential phenomenology. Findings are presented in the next chapter.

CHAPTER IV

FINDINGS

Introduction

That which stands out for us emerges against the ground in which we experience being in the world; for the parents in this study that contextual ground is others. The parents' experience is so consuming, demanding, and unrelentless that a sense of self is lost as their ground shifts unpredictably from their child itself to others in the larger world. Mirroring the cycling of their child's illness the parent shifts back and forth from the child and the frightening violence of the illness to an unhelpful, seemingly indifferent society. Like standing in the sand by the shores of an ocean, they feel a tenuously solid foundation for a moment, only to have another wave crash and shift the sand beneath their feet again. Within this shifting ground the parent's experience is engulfing, chaotic, frightening, frustrating, lonely and hurtful. Nevertheless, all of this is worth it to the parents because these are just children, and it is their child who is suffering.

This chapter presents the results of the thematic analysis with exemplar quotes from the participants. In addition, all words ion quotation marks are taken directly from the participants' transcripts. The participants included one grandmother, two grandfathers, one stepfather, and six biological mothers. The participants were members of seven families, the ages of their children ranging from 6-11 years. There were five male and three female children, all of whom had been diagnosed with Bipolar Disorder by a psychiatrist. All of the children were taking from one to five medications which included mood stabilizers, antipsychotics, anticonvulsants, antidepressants, stimulants, and others such as asthma and migraine medications. There was a history of psychiatric illness in all of the families. Demographic data appears in Table 4.1 followed by brief vignettes about the participants.

TABLE 4.1

Participant Demographics

Pseudonym	Gender	Age	Relationship To Child	Age of Child	Gender of Child	Psychiatric Medications
Stacey	Female	30	Biological Mother	11	Female	Lithium, Quetiapine Aripipirazole, Perphenazine, Sertraline
Peggy	Female	48	Maternal Grandmother	9	Male	Bupropion, Catepres, Risperidone
Chuck	Male	50	Maternal Grandfather	9	Male	Bupropion, Catepres, Risperidone
Susan	Female	42	Biological Mother	7 & 10	Female & Male	Methylphenidate Topromax & Methylphenidate, Trileptil, Buspirone
Sarah	Female	30	Biological Mother	11	Male	Risperidone Lexapro
Steve	Male	59	Maternal Grandfather	8	Female	Divalproex, Quetiapine Oxcarbazopene
Tricia	Female	34	Biological Mother	8	Female	Divalproex, Quetiapine Oxcarbazopene
John	Male	34	Live-in-boyfriend of Mother	8	Female	Divalproex, Quetiapine Oxcarbazopene
Dianne	Female	40	Biological Mother	6	Male	Olanzopine
Shari	Female		Biological Mother	10	Male	Oxcarbazopene Olanzopine Ritalin

Participant Vignettes

Stacey

The researcher drove through beautiful autumnal scenery in the hills of East Tennessee to a duplex in a small rural town to interview Stacey. She is 30 years old with a Bachelor's degree, works full time, and lives with her biological 11-year-old daughter from a previous marriage, and her new husband. Diagnosed recently after a long illness her beautiful daughter has been hospitalized four times, twice in the past year. Stacey has a wonderful sense of humor and irony. In her initial contact with the researcher she offered to share "some of the many stories, interesting information, and weird things that have become the norm in my house". The researcher and Stacey talked for many hours in her comfortable country living room.

Peggy

Peggy is a 48 year old maternal grandmother who has undertaken the parenting of two of her grandsons age six and nine. The eldest has been diagnosed with Bipolar Disorder. Slim and feisty Peggy shed many tears in talking about her experience. The children were left unexpectedly with her and her husband by the state children's protection agency. The interview took place in the sitting room of their small family home at the foot of the Smoky Mountains. Peggy has an 8th grade education and spent her earlier adult life raising her family. She has been integral in starting and maintaining a support group for parents of children with Bipolar Disorder. She invites others to join by saying, "together we can help each other and our special children".

Chuck

In his mid fifties, Chuck is Peggy's husband, the maternal grandfather of the two little boys. Welcoming, kind, and soft spoken, he sat on the edge of his seat, wringing his hands, and related his story. He has had to reduce his work load as a rehabilitation technician at a local

hospital to help in the day to day care of the children. A tree house that he built for the boys is proudly displayed outside in the yard.

Susan

Susan is a 42 year old woman with two children, a seven year old son and an eleven year old daughter both of whom have been diagnosed with Bipolar Disorder. Susan is divorced from the childrens' biological father who was diagnosed with Bipolar Disorder. She lives alone, but has a supportive boyfriend. Due to the demands of caring for two sick children she is unable to work outside the home and struggles to support herself with a home based graphic arts business. Susan and the researcher sat together with the cats on the couch in her home in the suburbs of a large city. Her creativity and intelligence became obvious as she and the researcher talked in a room that was cluttered with craft projects and totally lined with books. Beautiful medieval costumes sewn by Susan sat on mannequins around the room. Susan has a Master's degree with a specialty in psychology. She occasionally suffers herself from depression.

Sarah

Sarah is an attractive Registered Dietician working in a long term care facility. She is divorced from the childrens' father and has remarried. She remembers her grandmother who was valedictorian of her high school but suffered from the "torment, hallucinations, and hospitalizations of mental illness". Sarah loves to "zone out" for 15 minutes by reading and playing computer games and feels blessed that she can continue to work. She has three children, a young teenager who is doing well, her 11-year-old son who has recently been diagnosed with Bipolar Disorder, and a 7 year old daughter who was born with developmental delay. Sarah is excited about recent steps that she has taken in exploring surgery to address her weight problem.

Steve

Steve, a Vietnam War veteran carefully told the researcher that he is fifty nine and three quarter years old. His daughter, her boyfriend, and his 8 year old granddaughter moved back into his home 18 months before to get help as they cope with the child's illness. Steve was diagnosed at 45 years old with Bipolar Disorder although he says he had it for much longer. He is involved in daily caregiving activities for his granddaughter, taking her to school, playing with and watching her, and giving her medications. Steve's home is a small frame house located in the older section of a mid size metropolitan city.

Tricia

Tricia is Steve's daughter. Her husband died tragically and she is in recovery from chemical dependency. She works full time doing shift work and is very enthusiastic about a support group that is starting up in her area. Warm, friendly, and excited to tell her story her face lit up as she talked about eventually going back to school and pursuing a career in social services to help others. Her 8 year old daughter has recently been diagnosed with Bipolar Disorder.

John

John is Stacey's boyfriend and considers himself the child's stepfather. He moved from Utah with Tricia and the child, has an active caregiving role, and takes the child to school and doctors. He has developed a close relationship with his step-daughter and he was the one to whom the child first disclosed her plan to commit suicide.

Dianne

Dianne works in law enforcement, is 40 years old, slim and attractive. The interview took place in the researcher's office. Dianne brought a picture of her handsome son in his baseball uniform with her and she and the researcher sat it between them for the interview. Divorced from the child's father who has Bipolar Disorder, she is now in a stable supportive relationship. Dianne

also has another adopted child with a congenital disorder. Three of her siblings have been diagnosed with Bipolar Disorder.

Shari

Shari is 30 years old, slim, shy and very attractive. Her eyes pooled with tears that remained unshed throughout most of the interview. She expressed how much it helped her to talk to the researcher. She brought with her an organized folder of information to the interview which took place in a classroom of a rural school that her son presently attends, facilitated by the school nurse. Shari and the researcher met her 10 year old son in the school grounds. Walking along with his tennis shoes on his hands, and almost as tall as her, he enveloped her with smiles and a big hug. Shari is divorced from the children's father and remarried. She also has a younger daughter who has been diagnosed with Attention Deficit Hyperactivity Disorder. Her son has recently been hospitalized for violence directed towards her and his stepfather.

Contextual Ground

Three relationships dominated the parents existential ground of others, that with the child, the larger world, and with themselves. During the times that the child's demands lessened, the parents' attention turned to others, such as educators, health professionals, and relatives. However, there was little time left for their own selves.

"My Child"

> "And from this chasm, with ceaseless turmoil seething,
> As if this earth in fast thick pants were breathing,
> A mighty fountain momently was forced." (Coleridge, 1944, p.73)

Before the parents described what stood out for them in their own experience they invariably talked about their children and the illness. Their life is grounded in the child, and the tumultuous symptoms of the illness form a background from which meaning stands out. All of the parents described in vivid detail some of the unpredictable behavior that they and the child have experienced as a result of the illness, calling it "exploding", "meltdown", "going off" and the "volcano inside." Stacey's description exemplifies what the parents told the researcher about their children's behavior at home and school:

> And, um, as far as the crisis go, we've had everything from she hears voices, wants to stay in the closet, from collecting feces smearing it on the wall, um, head banging, crying. She screams until she turns blue and has a headache the rest of the day. On top of attacking other kids, she was hurting herself, she had long hair at that time and was wrapping her hair around her throat in class until she was turning blue, she was scratching herself on her arms and her legs, and she was trying to hurt other kids, she was scratching other kids, drawing blood.

Chuck said that there was "so much cussing and kicking and snorting and steaming, hitting brother, and hitting, oh he's hit my wife and bruised my wife so bad she looked like a purple dinosaur, she had bruises everywhere." Susan likened it to the end of the world, "if you look at her wrong, and she's in hysterics, she's sure that you hate her and that, you know, the... LIFE, the sky is falling and Armageddon is coming."

The cycling and polarity of the symptoms was evident to all of the parents. For some it was a daily cycle, for others over two or three days. Describing her child's cycles, Sarah said,

"I've seen him fall in a day's time from the euphoria down to the low. It's usually not a trend of several days. But when he gets low, he gets low." The following quote explains the cycling:

> the way it works is when you're on a manic mode, right, depending on what you're doing, you can be top of the heap, or you can be a Beethoven, or you can be Mozart, or when you're at the bottom of the heap, you're like a jelly fish, you're just laying there doing absolutely nothing. (Steve)

The clear cut polarity of her daughter's symptoms was somewhat helpful to Tricia:

> She goes like three or four days and she's on a high and every things great, and in like two days it's kinda er, I'm not really sure, she's afraid to be alone, she very anxious, she doesn't want to go to school, she doesn't want to talk to…you know. Then all of a sudden, she's humped. Well, it's a, she has, she does have a clear-cut pattern. Which is helpful, you know. (Tricia)

Polarity was also reflected in the parent's thoughts. Chuck said, "there's times we may just be rejoicing because our child is, you know, is not depressed, and not driving us crazy. And, and there's times that we, we're sad, you know. There's always two sides to every story; there's always the good and bad of it. Are they going to be the next Ted Bundy or are they going to be the next Abraham Lincoln?"

"My Chaotic World"

Managing the illness is "all encompassing" because during the times that the symptoms are remitting the parents shift to that which forms the horizon of their experience, that of others in

the extended world. This includes relatives, professionals, and close and distant social contacts. Here they find an overwhelmingly disorganized, judgmental and unknowledgeable community. In their search for help to ameliorate the impact of the symptoms for themselves and the child they find that others are not as embroiled or invested as themselves:

> and these psychiatrists will not communicate with the teachers, and tell the teachers, and they don't know what's going on because they won't talk to each other. I mean it's like a fence and here's the psychiatrists can't talk to teachers and the teachers can't talk to psychiatrists. They don't understand one another and when they do talk there is all this bickering and arguing and it's not meeting what we need." (Chuck)

"But in Going Through All This There isn't Really a Me"

Within the contextual ground of others it is notable that the parents in the study reported losing their sense of self. Compelled to manage the illness and deal with the overpowering symptoms, the parents talk of "having to be there for the child", and, "my time is not my time, my time is all for her." The parents cannot "go off the way everybody else does." Steve feels compelled to put the child before himself. He said, "The biggest thing is to just be there for her, you have to be able to help her. It's a major consideration to know you have to provide for this feel of hers." Stacey's words sum up the feeling of loss of self, "in going through all this there isn't really a me, there's always a process, always something going on." This experience was echoed by other participants as they discussed the obliteration of many aspects of their individuality and loss of personal boundaries:

> Every day's different. Like yesterday, I was, you know, nothing bad was going on, it was just, okay, I just want to be alone. I don't want to deal with it any more; I just want to be by myself for a while. And it was really like, you just can't do that. (John)

> And, and there's times that we, we're sad, you know, you don't want to but sometimes I take it to work and think about it, or I'll, I'll take it different places with me. You can't just throw it away; I mean it's always there. (Chuck)

Sometimes the loss of choice and individuality becomes unbearable as it did for Shari, "the other day I had to break down and cry, I don't have me anymore."

Thematic Structure

Creating a theme is a way of linking the threads of underlying meanings. The themes that emerged through analysis of the interviews in this study are (1) *"it's always, always: engulfed in chaos"*; (2) *"my hands are tied: scared and frustrated"*; (3) *"on the other side of a dark curtain" alone and shunned away"*; and (4) *"I cry so many tears on this child: it hurts but it's worth it."* . The themes that emerged were represented in all of the interviews as the participants in this study spoke intimately and at length about their experiences. One theme was not dominant over the others but all of the themes were interconnected in a bidirectional manner. The thematic structure is diagrammed in Figure 4.1. The following narrative describes the themes and the sub themes.

"It's Always, Always: Engulfed in Chaos"

The temporal dimension of their experience was very strong for the parents in this study. Sub themes that emerged in their experience of time were *"constantly diligent"*, *"you just fight*

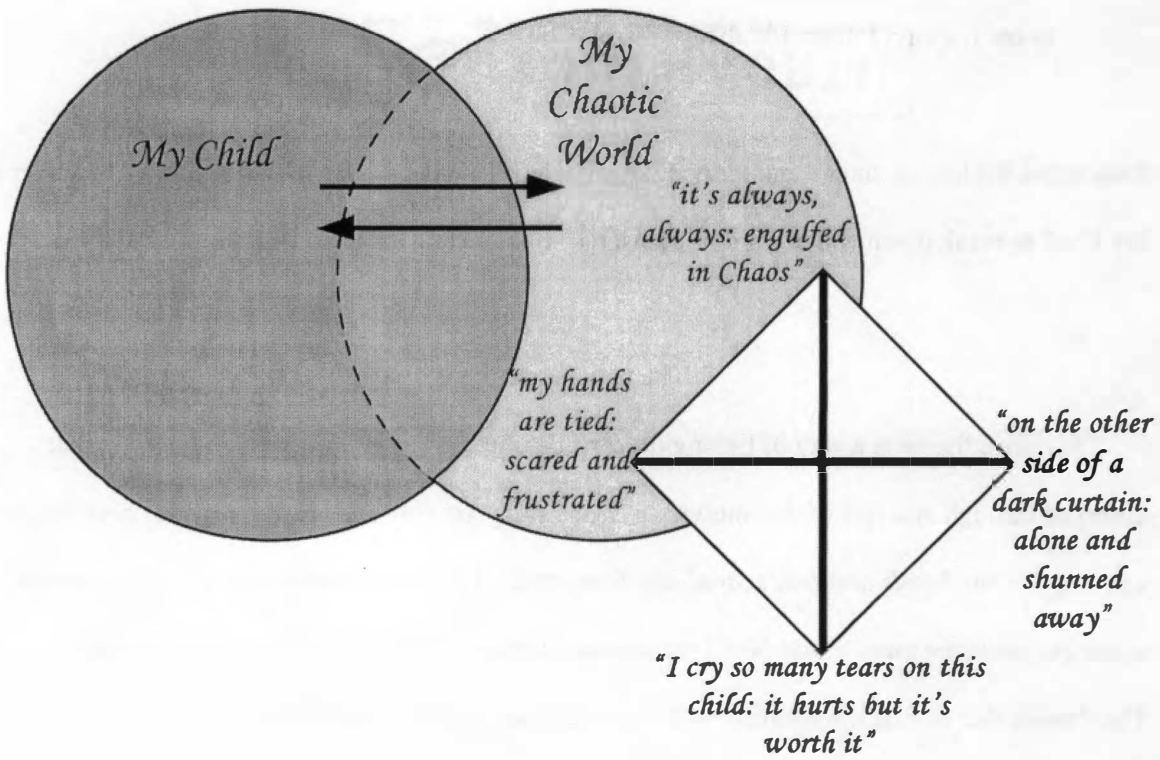

FIGURE 4.1: Thematic Structure: The Experience of Parenting a Child with Bipolar Disorder.

every day", *"engulfed in chaos"*, *"the roller coaster"*, and *"the diagnosis."* The participants talked about always having to either cope with crisis or be involved in the extensive management of the illness, "every day, hour to hour, minute to minute." As Tricia said "I'm going, I'm going, and I can't stop", and Dianne noted "you go on and on and on and on and there's no break, there's no stop", and for Shari, "one minute it's just a whirlwind and the next you can breathe." Even when not actively engaged in a task the parents feel like they have to be constantly available, ready to take care of a crisis. There is "always something going on" and "it's constant but it's unexpected." These quotes illuminate the extensive management and constant readjustment:

> You know it's faxing something here, filling out a paper, mailing it there. It's calling the insurance company, it's calling the hospital, it's talking to the school, it's talking to her therapist, it's having the therapist come to the house, taking her to another therapist at their office, it's always, always. (Shari)

> And it's like you've got to constantly be on your toes, but you've got the, uh, make it all as normal as possible. It's like OK. Bad news, how do you do that; it seems like it's a matter of adjusting all the time, every day, hour to hour, you know, minute to minute, you know. (Tricia).

Many of the parents talked about a constant feeling of awareness. Shari said," I never get too off guard because it makes the situation worse. It's like shock, you still have to keep a reality there." They cope by keeping their cell phones with them at all times. Stacey describes it:

I'm on call in fact and have to always be able to have somebody get in touch with me. It's just, even at work, you know, I have to keep my cell phone with me even if I leave my desk is, uh, I don't, I don't like being so attached to a phone. Uh, I would like to have some free time. (Stacey)

"Constantly Diligent"

Wrapped in the unrelentless pull of caring for their child the parents talked about how they need to be "constantly diligent" in order to protect their child and others. Sarah said: "I stay on top of—I just watch, very, very protective." Many talked of vigilantly watching their child:

But; you have to be constantly diligent in watching him for stuff. You know, I had to watch like, how's the cat, how are they reacting to the cat, you know. Stuff like that, I have to keep extra, touch base with the teachers, you know, how's he interacting in school, you know, Uh, "what's he doing here, what's he doing there", you know. (Susan)

Because even for me to take a shower it's scary because I don't know what's gonna happen. I don't know if he's gonna hurt his younger sister. So it's always on my mind. I made a joke that you know how I always say it's a three ring circus, well I'm in the three ring circus. I see everything. How can you see everything? I don't know but I do. (Shari)

She was picking out trees that she wanted to hang herself from. I talked to the maintenance people about cutting cause that's one of the places that she said she could do it from. We were just very, becoming too overly protective, and not letting her go out too much by herself. (John)

Many of the parents talked about sensing what kind of day the child was going to have:

> I can look into his face, I can look into his eyes, and sometimes you know it's gonna be a good day or it's gonna be a bad day. There's a little something in their eyes, I can't really explain it to you but you can see it. So I'm watching, (Chuck)

When her grandson first came into the house, Peggy and Chuck had to lock their bedroom door at night for their own safety because the boy was very violent. Now she talked about watching him, as she finally allows a long awaited sleep over in the tree house:

> I'm watching him constantly night and day, What if he has a nightmare or running out there falls six foot to the ground, hurts himself, you know, I'm a nervous wreck, you know. We stayed out there all night to be sure they're all right. (Peggy)

The parents' diligence is also reflected in their continuing search for knowledge and resources in order that they might advocate for their child. They talk of "educating themselves", "trying everything", and "wanting to know everything so I can be a better parent for my child." All of the parents talked about studying, and having file cabinets full of records. As Sarah said, "I'm the paperwork hound." This quote describes the diligent search for knowledge:

> And if it takes hours to do it, Mammaw's going to be there to help, if its something Mammaw doesn't have a book on, she's going to look it up on the net. You know, if they don't have a book, I'll go borrow a book, you know, we're going to find it out. (Peggy)

Describing the need to educate themselves sometimes resulted in tears and anger because they feel like they have to do so to protect their child:

> I had to try, because he's in special ed and because he's Bipolar, a lot of people don't think about it, but there's laws out there to protect these children, but there's also laws that would go against these children if you don't keep tabs on them. So I constantly have to research, not only the laws we have but the laws they're making and which changes - don't pull that right from my child, my child has a right to a education, my child has a right to a life, my child has this right and don't you pull it away from him because he's on medication, or because he's a little bit different from another child around him. (Peggy)
>
> We're just kinda a stay at home type people. Now we're getting out and we're meeting people that are so much more educated than we are. And I don't understand half what they're saying. I have to, you know, either copy down what they said or get a book and er, go back and say OK, read it four or five times to understand what they said. (Chuck)

The parents' diligence is also reflected in their efforts to educate others. The following quote describing a time when Stacey addressed her child's schoolteachers exemplifies this dedication:

> And uh, I basically held a "What is Bipolar" session. I went in, I was armed with folders, I had folders for each of them which I had made up, articles, uh, from magazines, from the Internet, uh, medication information. I had made up a three page information sheet just on my daughter. And, I just sit down with them and told them all. And, and I really think that helped. (Stacey)

> And I lay it all out there, I explain it till the cows come home, I don't leave a question in their head. So, and just, I do; I educate, educate, educate, educate and I think that's the way to stop there being a stigma, is to educate. I just do it every where. (Susan)

The parents described themselves as "resourceful", "constantly figuring out", "trying everything", "constantly readjusting", and "trying to find their own way." Sarah talked about her resourcefulness, "I'm pretty resourceful too; I'll tap into whatever I can. And if I hear about a program, I'm not too proud to call and ask, 'Can you help with this'?" In their effort to get help for their child during the long painful journey to diagnosis, two of the parents were advised by their church to have an exorcism performed on their child:

> They convinced me she was demon possessed. I was convinced of it, and so I took her to two different churches to get her the exorcism because I was like, there is no way a child like this can go into such a rage and it takes two grown adults to hold down a six year old child. I thought there must be some kind of supernatural thing going on (Stacy).

It was often confusing for the parents as they tried to modify their child's behavior because usual parenting strategies didn't work. According to Susan, "That's, that's the big thing is trying to find something that works. Uh, it's hard; it's really, really, really hard. Because time outs don't work, taking away privileges doesn't work; trying to find what works is horrible because nothing works. Really, you know, I've gone to, I have this long, long list of different things that I've tried." John also mentioned that it was confusing, "It causes more confusion for me sometimes. As far as what do I say, and when do I say it. As far as that goes. As far as, you know,

what's cool, how to do it, what do we say, what do we do?" Tricia is also figuring out, "And the thing again, she, you know, she's a child, but she's not a normal child. And then I have to figure out what is normal; I have to figure out, what is her normal as opposed to what you see, what we, society considers a normal child. I have to figure out what is normal for her. "

"You Just Fight Every Day"

Another everyday experience was that of having to fight. When describing their efforts to get appropriate treatment the parents talked about "fighting for the child against the system" and "it's a battle everyday". The parents' experience with fighting reflects strength, perseverance, and times of empowerment. They get upset by the prospect of themselves or other parents losing their strength or the resources to continue fighting and advocating fiercely for their child:

> Like I said, I'm in there fighting. They're just children, just children, and there are parents can't get help or therapy and they are thinking the only thing I can do is to do this even if this will be the last part or thing that I will do, you know, it's just stick it away in a mental institution, or, you know, making the state take it, or let it go into state custody, or even into jail so it can get the medicine it needs, so it can get the help it needs. This is the sacrifice that some of these parents are making for these children. It makes me angry; it makes me angry that we have to fight all way around. All the way around. (Peggy)

> No, no, no, no, 'cause that's just your easy way of brushing her off on somebody else, Uh uh. I'm going to learn how to deal with this; but I'm going to make you learn how to deal with this. (Tricia)

> You want to put a child, with my, and my father is alcoholic, was an alcoholic, with this much possibility in his genetic background of bipolar, you want to start him on a trial of Ritalin". I said, no. NO, NO, NO, NO, NO, I won't allow it. And I immediately called up Tennessee Voices for the Children and I said, "Who can you recommend?" I said, "This is a no, no". (Susan)

Another aspect of the fight involves the daily struggle with the child. Shari explained it, "Every morning you don't know what to expect, that battle every morning. I feel like I'm fighting a whole lot." However, for all of the parents it is unequivocally a worthwhile fight as exemplified by Chuck's statement:

> It's just, just a fight of, but it's a, it's a fight we fight daily, but it's a fight I'm glad to fight. I'll fight it as long as I can, as a breath in my body, because there's a, there's a, it's a, there's a way to, to reach these kids. Yes that's it, you just fight every day. (Chuck)

"Engulfed in Chaos"

As mentioned previously the parents described always being "engulfed in chaos", evident in the following quote:

> It was a fight to get her to eat supper; it was a fight to get her to do homework. You know all evening it was all about her and getting her into bed at a decent time was a rarity, we would be up 'til 10 o'clock engulfed in chaos. (Stacey)

When the parents are not dealing with the symptoms, they are absorbed in the immense task of daily negotiating with a system that also seems to be engulfed in chaos, lacking communication, and without a continuum of care:

> "I'm not getting good continuum of care. That is the problem with everybody. They want to take somebody, put them over here, because you're not mainstream. And I think that's the problem is we're so busy that everybody's got to be put on the market, because you're slowing up traffic, slowing up mainstream." (Sharon)

> We can overcome this if we can quit bickering among the psychiatrists and other people if some how we can join together as a group, because we get psychiatrists together and they can't decide on the same pill. They'll argue for ever and ever and they'll argue, one give one pill one will give another, so you're back to trying to decide what pill to give. They need to just work together, it's not me, it's not you, it's the child (Chuck).

"The Roller Coaster"

Pervading the sense of chaos is the uncertainty about what they may face that day and in the future. The daily uncertainty is described by several parents as being on a "roller coaster". For Stacey, "it's a really huge spectrum of up and down, it's a huge roller-coaster" and for Susan "Yeh, roller coaster, waiting, waiting to go down. And you watch. Sometimes you sit there watching yourself going, here it comes, where's the chocolate? You never know when it's going to the roller coaster is going to start up hill, back down again. You know, it can be all dressed and ready to go and it hits. It can be as sudden as that." Another example was given by Shari, "it's

been a roller coaster, anything from him hitting me to breaking his bedroom window out, 'I hate you, get away from me, you don't love' me even to the point he wants to die."

Although the parents feel like they are on a roller coaster they all talked about working hard to provide structure, consistency, and stability for the children, even though their ability to provide structure was often questioned by others. Dianne explained, "We have always had a structure, my kids have always had a set meal time, they always had a set bed time, I've always read to them every night, set bath time, they get up at a set time, they don't sit and do nothing all day. I mean we have a very structured life, but it was always my fault. 'If you had more structure, he wouldn't be so out of control', and I'd be like 'Yeh'. At first when he was younger, it would just crush me and I would just cry and cry."

"The Diagnosis"

A pivotal episode in the parent's experience of time was the diagnosis. All parents related how things seemed better since the diagnosis and some order was being brought to the chaos. Each believed that receiving a diagnosis was a relief because they knew that the child had been sick for a long while. The period prior to the diagnosis seemed to be an interminably long, hard, search for help. This journey usually started with pediatricians or family doctors. Often the parents were told the child was "just very active". As Dianne relates, "It's been going on four years I've been questioning the doctors. I asked this doctor, I cried when I asked him, but I said is there anyway that we might put him in a hospital or a retreat or something and maybe monitor him at length, 'Oh No boys will be boys'." Eventually, all of the parents took the child to a psychiatrist, in almost all cases the primary diagnosis made was Attention Deficit Hyperactivity Disorder and the child was started on stimulants. The parents sometimes complied against their better judgment:

I'll never forget when he said my skin hurts. He climbed the walls, he jumped out of the bath and tried to climb the wall when he was rebounding [from the stimulant]; the doctors said that's just a typical rebound. According to what I read on the ADHD website, there's irritable and tired, but then the absolute jumping out of the skin, you know! (Dianne)

The parents found it hard to rationalize the reluctance of psychiatrists to provide a diagnosis, especially if there was a strong genetic history. All of the biological mothers described how they felt that there was something wrong with their child from a very young age:

Well, he was a very active baby, very, very hard to get to sleep so when we went to pediatric person, pediatrician to pediatrician, and they said well, it's like colic but he doesn't have colic and that was very key because he was always, I mean, I can't even describe how active, even as a brand new born, just moving constantly, and he seemed, although very happy, he seemed very irritable all at the same time. (Dianne).

Trying to get him diagnosed the initial diagnosis. I've had a depression triggered by that. 'cause it was just, ooh, it was just miserable, it was just miserable. Cause I was going round and round and round and round and nobody was listening - Nobody! (Susan)

Hence, all participants viewed the diagnosis as positive because, as Shari said, "I knew know how to tell my story, I could get them to listen as before I just had an unruly child." Two mothers expressed guilt at feeling relieved. For example Shari said, "Well this is going to sound so awful whenever I tell you, I felt relieved." Tricia felt the same way:

When the doctor finally said the word bipolar it was like a tremendous relief. I don't know how to explain it. She finally had a name, it had a name, IT had a name, not her. IT had a name, you know, and I don't think people realize that unless you give it a name a name, there's nothing a parent can do. Cause I can go look up mood disorders and its 50 million out there. You know, whatever, which one do I look up. It's like now I can go and I can look up bipolar one disorder in children, bipolar one disorder in adolescence, bipolar mood disorder as she grows, you know, I just, I can read and it's really helped a lot , and I finally came home and, "Oh my God," and I said "Yep"! (Tricia).

One of the reasons that the parents viewed the diagnosis as positive is the effectiveness of the medications. Many of the symptoms, although still present, had been ameliorated. The medications "very much helped", were "miracle medications" and "you can definitely tell a difference."

Sarah however was still struggling with full acceptance, mainly because two psychiatrists were in disagreement:

And it's hard to accept that diagnosis that I have a child who is a bipolar kid. I still haven't fully accepted it, because I'm still in a phase of questioning. You know, why is it one doctor feels that he is bipolar, and then we've got another doctor in the same field that has seen this physician's notes and knows the background of Matt, and has seen all the medications he's been on. Why is it that there's two different professional opinions? Because I've seen a lot of it, what I call a manic phase, or the high, euphoria. I've seen that in him. And that's why it makes me think, yes, he is, but I'm still in denial. It would help, I think. (Sarah)

Bearing in mind the all encompassing, engulfing, and constancy of the experience helps us to understand the powerfulness of the following themes that describe emotion.

"My Hands Are Tied: Scared and Frustrated"

The parents described intense emotions of fear and frustration. They liken it to "having their hands tied", with no one "paying attention", unable to move forward, to protect themselves and their family. It is a terrifying feeling because they fear what will happen if they are unable to get their child satisfactory treatment. The parents' source of frustration fell into three sub themes, the educational system, the healthcare system, and insurance.

Fear was woven throughout all of the parents' transcriptions, a pervading sense of anxiety and danger which included being afraid for the safety of their child and others, fear that professionals might harm their child because they were uncaring or lacked knowledge, and fear of what the future might bring. According to Chuck, "There are dangers there for them hurting him, there are dangers there of him hurting them." The parents all expressed an excruciating fear that that the child would hurt themselves physically or that they would lose their child forever through suicide.

> There are some people just don't have the right chemical balance, so that when I'd seen my son that way, my first and foremost thought is, "I don't want to be a parent of a child who kills himself, I don't want to see my son in jail or in prison. I don't want to see his funeral before I die, I don't." Very scared, very scared what teen years are going to be like. This time I need a tissue. Because, I love him so much. (Sarah)

I have a really, hard, I had a really hard time; the scary part for me is when she feels like she doesn't want to be alive anymore. I have a, I have, I don't understand, I don't understand that feeling, I've never been there. (Tricia)

Chuck found the fact that he and his wife had to make difficult decisions without counsel very scary, " now that's kinda scary to know that my wife who had an 8th grade education knows more about the drugs and what he needs than what the psychiatrist does."

Violent and scary situations often permeate the parent's lives. All of the participants were afraid that their child would harm others physically as the child enters a manic phase and loses their underlying loving personality. Shari who "carried bruises' said that she had to face reality when her son "was little, and a bigger boy, I don't know, made him mad, and he jumped on this bigger boy and started hitting his head into the ground, that was my bell." For Chuck fear was a very strong theme "and I've been scared for my wife and stuff, he was very violent when we got that child." John described his stepdaughter's suicidal thoughts, "it's kind of scary when an eight year old comes to you and describes to you exactly how she wants to go, and she doesn't want to live any more, and she wants to die and she wants to do it this way and, you know, believing that she wants to go." The following quotes remember particularly terrifying incidents:

And I'm on the seventh floor, and I'm like scared to death, you know, cause I know there's like an exit that goes out, because the seventh floor door is actually to a patio. The rest of the company, the rest of the other stories do not have one. And I thought, Oh my gosh, what is she going to do. I mean, I didn't know what she was going to do. (Stacey).

He sees dead people, he sees scary men without faces, he sees, you know, scary men and

they don't have faces and they come and get me. So, you know, it doesn't happen all the time, but you can tell by the look on his face it's real. From the age of three, he has the most incredibly gory dreams - people ripping hearts out, blood. (Dianne)

When the researcher asked Shari if she would like to describe her experience of parenting she likened it to being in the middle of a horror movie:

Well, it's kinda like being in a horror movie, to me that would be it. You're always expecting something, but you never know what it's gonna be. You have that anxious feeling always, always... For him what's normal may not be normal for everybody else. For me there is no normal and that's scary. I just can't see in front of me and that's scary. I just can't let it roll off my back onto my child. (Shari)

Fear of having the child taken away from them because of their powerlessness in the face of others' misjudgment was also paramount in all of the discussions. The following quote exemplifies how the parents spoke of worrying about being mistakenly identified as an abusive or neglectful parent:

I have DHR (Department of Human Resources) involved in my life now. And that hurts more than anything. Jay took a knife to his step dad and when his Dad took his arms to hold him Jay bit him, and holding him left a bruise right there, Ok, so we had to go through a thing called family options. So we had basically had a lady that came to the house and lived with us (Shari).

The parents were also afraid that lack of knowledge and unsympathetic attitudes from health professionals or educators would harm their child emotionally. Peggy revealed that her six year old grandson had been taken away from school in handcuffs. She and others talked passionately about their fear of inappropriate reactions from school authorities:

> They say, all right, he's Bipolar, you deal with it. And these children are being passed around and I go WOW, if the teacher's doesn't, if she's not equipped, if she's not knowledgeable on what to do, that this child is sick and needs the help, then he's out of there, he's expelled - They're not gonna, they're not going to deal with it. So it's back to the parents again, or it's back in the court systems or where ever. They're back in the state, and sometimes parents just have to deal with all this going, this cycle after cycle after cycle, 'till they just say, "All right, I just give up! Go ahead, take the child, put him in state custody in a mental institution, I love my child, I want the best, you don't feel like I'm doing a good job, please take my child so he can get the best help". And that's sad, but that's what a lot of things that's happening. (Peggy)

> if she goes into class one day and is headed down and hits her bottom at school and starts with the "I don't want to be alive." And this is what scares me; I know the first thing they are going to do. They're going to call me, they're going to call the police, they're going to call the hospital, they're going to call everybody they can; is there something going on at home? You can bet the first place they always have to start "is there something at home?" No, there's nothing at home; this is her. (Tricia)

A recurrent experience was fear of losing the progress that they had made so far because of health insurance issues. Susan said "like the fact she'll go off the insurance or something like

that, that's terrifying. I really lucked into seeing, getting Dr. Listener, you know. Its, Oh, please, I hope she never leaves, never quits her practice, while my kids are, you know. That's scary, like the fact she'll go off the insurance or something like that, that's terrifying."

Dealing with others was extraordinarily frustrating to the parents, resulting in anger and tension. In addition to talking about feeling frustratingly helpless, they were frustrated by others' judgmental attitudes and lack of knowledge. As Stacey said, "I was just learning about it myself and I'm sitting there with these people that I'm supposed to educate when they are supposed to be the professionals." Even as they educated themselves and gained insight into what they and the child needed, they were often unable to get this help. The intense level of frustration is reflected strongly in all of the transcripts.

The Educational System

One of the prime sources of frustration was the educational system, "it's pretty bad the school stuff." Although all of the children were reported to be highly intelligent (several qualified as gifted) the parents talked about how they were faced with huge barriers to their educational success. The parents' stories described unknowledgeable, unsympathetic, incompetent, and judgmental educators, inflexible rules and regulations, and inappropriate and sometimes illegal actions. In Steve's opinion, "the education system isn't overly bright about all of this. Uh, in fact, ---- DUMB! Just pure dumb. They're pure dumb, they're dumb, OK." In talking about her dealings with the school system Stacey reflected. "The experience hasn't been good. No it's been horrible, absolutely horrible, I mean in my opinion those that work in the school system need to be educated, even her school counselor, which this shocked me."

All of the parents expressed the opinion that the level of knowledge about children's psychiatric illness in general and Bipolar Disorder specifically was very poor. Chuck found no excuse for this:

> Especially if you're a Special Education teacher, FOR GODS SAKE, you need to do it. There's no excuse for a special education teacher not knowing what Bipolar and all these different problems are, ADD and ADHD. There are Special Education people that I have met and they don't know what Bipolar is, and they are teaching the kids at school, and there is no excuse for that. (Chuck)

The parents fully understand and support the need for the school to have a system in place to protect the teachers and other children. Nevertheless, all described situations where they felt that there could have been more flexibility and better judgment in order to both protect others and facilitate their child's education. They talked about how their children spent many days in detention and suspension because of impulsive remarks, adding to the disruptions that the illness caused. Peggy told this story of a recent particularly frustrating episode:

> It's very frustrating; it's very frustrating! you're expecting them to call and say, "You need to come up here, he's hurt another child", you know, and when they call, and you're ready to go up there, and it's something off the wall and you're just ready for a nervous breakdown because you're just imagining the worst because you know this child's potential. And you find out the reason they called you up to school is because he told an intern her breath stank! It's frustrating, it really is, I want these people to see and I want 'em to learn. (Peggy)

Many of the children had been to multiple schools because of their parents search for a better environment or being "kicked out." Stacey's 8 year old daughter had been in five schools, Dianne's son had been "kicked out" of nine preschools. Many parents described educators as

uncaring and dismissive, "I see it, even in teachers and people who know better, you know, educators who will, will say, "there's, there's that retarded class or …". Stacey talked about feeling appalled by a note from a teacher. "She was having so many problems all the teachers could do would be to send me notes and be very frustrated, it got to the point I was getting what I called obnoxious notes. One of the notes I received was, 'If your daughter can't do better then I can't help you'. I was just totally appalled, just totally." Other stories decry the lack of interest and negativity:

> but any time the phone rings it's Oh, Oh, what is it? You know because it had got to the point that every day I had to go and get her from school. They couldn't deal with her. They didn't want to try and understand what was going on. (John)

> And I had finally had enough with the school system, 'till just couldn't take it any more, so I took the book (The Bipolar Child) because I'd heard 'he was bad today, he was bad today, he was bad today'. Never once, 'yes, we had a rough morning, but he done his best so don't be too hard on him' - never once. It makes me angry; it makes me very angry. I've even heard, even teachers refer to them as 'the other children' (Peggy).

All of the parents cited incidences of intimidation or inappropriate actions on the part of school personnel using the terms "talking in codes" and "being ganged up on":

> When we met last time at the IEP (Individual Education Plan) meeting, it was just supposed to be the special ed teacher. It's at 7:15 in the morning. And I'm walking, thinking, "It would take five to ten minutes to sign the paperwork." I walked into a room

> full of all three of his teachers, the principal, the lady over special ed for the city, and the special ed teacher. And I felt overwhelmed, I felt like I was ganged up on. It's put me on the defense, big time. And I felt like I was misled, and here they are, talking amongst themselves, pretty much making decisions for Matt, and asking me for input. And I'm over whelmed. I did not want to sign those release forms, but I did it just to keep the peace. (Sarah)

Many of the parents were anxious about the school administrators calling the police and treating their child as a delinquent instead of a child with an illness. Steve said, "you don't send these children to detention or to the office, etc. You try to resolve the problem in the classroom, in the classroom, constructive, that's what they need to do." Finally Tricia expresses the frustration felt by all of the parents. "You know, I'm, I just don't know what to do. I, in that respect, I don't know what to do. I've thought about home schooling but I think it's good for her to be in school."

The Health Care System

Another source of frustration for the parents was the health care system, generally described as unknowledgeable, uncaring, and inattentive. The lack of knowledge among health care professionals such as psychiatrists, counselors, pediatricians and general practitioners was incomprehensible to the study participants:

> I don't feel it's my responsibility to know about dosage, and it's not my responsibility to know if this medication is taken with this one its going to give you this kind of reaction. You know I should have went to medical school if I'm supposed to know that stuff. So, I

was very disappointed and feel that I have done a lot of the legwork and probably deserve the pay that he gets for what is done for her (Stacey).

The parents in this study commented that psychiatrists were unable or refused to spend more than a few minutes with them every three months, nor did they educate them about the illness or the medications. They revealed lack of trust in the psychiatrists' knowledge of childhood bipolar and medications and some relayed stories of feeling abandoned:

> He did see a psychiatrist once in a larger town; I wasn't happy with that situation. I wasn't happy that we go into the room and they weigh him, speak to me five minutes, hand me a whole handful of prescriptions that I have no earthly idea what they are, or what they're for. And tell me I'll see you in six months and if you need me, you can call me. Well we needed him, we called, and he was at break, lunch at 8 o'clock in the morning, because we were having crisis, we were having heavy seizures. And that's really frustrating; you know, if I need to get in touch with help, our hands is tied. (Peggy)

Many of the parents talked about how it was frustrating when professionals treated them as if they were novices, and occasions when they felt misjudged stood out very strongly for all of the participants. The following quote describes a common frustration felt by all of the parents:

> I said it nicely, I'm like, "We have tried everything!" But inside I wanted to say, "Look lady you don't even know". It just it frustrates me when someone gives me a suggestion and acts as if I've never tried something. 'Haven't you just tried telling her no and sticking with it?' I'm like 'OK'. That is probably the most frustrating thing that I deal with is. And

I feel like I have done a lot of work and I am very educated on it. It's totally degrading. (Stacey)

Many talked about times when they felt that other health professionals were reneging on their responsibility to serve their children. Sarah felt that her general practitioner was dismissing her son now that he was under the care of a psychiatrist, "It's like, 'this is my realm of practice, and this is out here'." John felt threatened by a doctor, "And one of the doctors, they were talking about having me put in jail because I can't sign the papers. Me and her Mom's not married. And they threatened to take me and have me arrested for neglecting the child's health if she's not seen by a certain time. I don't have the legal backing even though I am involved." In addition, Tricia talked about the lack of knowledge among pediatricians about psychotropic drugs, "every time he would put her on an antibiotic, I would ask him, you know, if this was going to interfere with this medication, 'What is this medication for?' What! You're a doctor and you don't know what this is. OK, and I explained it to him."

On the other hand good medical care and good educators are described as blessings. In particular the parents were grateful for schools such as magnet schools that were more accepting of differences and doctors who treated the parents with respect, as equal partners in the child's care, and who listened to them, as shown in the following excerpts:

Dr. L is wonderful, she's been a Godsend. I don't know what I would do without her because she comes back there with you and we sit there going back and forth and back and forth going, "OK now let's think about this. What are we seeing here?" And we'll get these little ah-ha moments. And she just doesn't, "OK, we're going to prescribe this", she

goes, "OK, here are our options and we could do this, we could do this, we could do this, my gut instinct is to go with this." (Susan)

When we moved back here, he got angry the first week, and pushed the teacher down to the ground because he got so angry at her. Now, he could have been suspended, expelled at that point. And I remember talking to the teacher, just crying over the phone, saying, "Please, please, just give him a little bit of time. He's a good kid. If you give him the time, and show him you really are listening and care, he'll love you." And I got lucky that day, lucky that week, lucky that year, because she could've really just said, "Listen, I don't want to deal with this." But she did, she still continued to care, which helped me and my son both. (Sarah)

In addition to schools and health professionals all of the parents talked about feeling frustrated by society's attitude in general. Susan summed it up, "It was very frustrating, it was very, very frustrating. Most of the time they just glare at you, doing this, 'why doesn't she take that child out, kind of look'. "

"And Insurance is Another Huge, Huge, Issue"

All of the parents talked about the frustration of financial burdens and insurance issues. Again, inflexible rules and restrictive coverage acted as a barrier to the child's recovery and success and prevented some parents from exploring other avenues of help:

my husband lost his job right before Christmas and we lost our Blue Cross Blue Shield and now we have to switch to a clinic further away and it's gonna be three months until

we can actually see a psychiatrist so we are just seeing a counselor now. Too me, I know they are doing all they can but it just scares me knowing that right now, in all reality, he does not have a doctor, and it scares me that I'm in a place where if it gets to the point that, hey I need help, I don't have it right now. (Shari)

Financial worries were acknowledged by all of the participants. The illness is expensive to manage, insurance may only pay 50% of a doctor's visit, and the multiple medications are expensive. Susan talked about her financial struggles, "I'm here trying to build a graphics art business and to make enough money to stay at home because of all these crisis that come up with the kids, you know, and it's like, 'Oh good, here I am with absolutely no money and my transmission has just died'." John was unable to get the recommended counseling, "I wouldn't mind going to therapy or stuff like that but right now, I don't have the money to do so." Peggy also felt that the state system was not helpful when they placed their grandchildren with them, "the state could have been more helpful by stating, 'I know this child has this problem and we have these programs out here that would help you', they could have done that." The parents were aware that governmental support did not always to extend to those with a psychiatric illness. Tricia wondered, "But I don't know if, say for instance, I was working somewhere and I needed to take off for a period of time if that would be covered under the Medical Leave Act because I don't think that, like I said, there's not that much of an understanding of it. So I don't think they realize how serious it is."

The parents revealed times when fear and frustration overwhelmed them culminating in passionate and emotional releases:

there's times that I just want to go somewhere off in the woods somewhere by myself and kick, cuss, and snort, and cry, and do what I need to do to get whatever frustrations I have out.. (Chuck)

Very alone, very alone. Like I have a sister she just had her first baby and she called me the other day, like, 'isn't there something you can do' I just broke down and cried right then its like, I'm doing all I can and I felt like if you think you can do any better you come get him, let's see how you do. (Shari)

"On the Other Side of a Dark Curtain: Alone, and Shunned"

Like Shari, all of those interviewed described being distressingly alone in their world. Because "people don't understand" they feel isolated and rejected. This theme describes what stands out for the parents in their experience of self. Sub themes emerged of feeling blamed, *"and so it was all my fault"*; alienated, *"shunned away'*; and desperate for help *"I need help.*" The loneliness is a profound experience for the parents in the study. For them it is both societal and self imposed. Tricia summed it up "But a lot of time, it's just, I feel like I am alone." As Steve so eloquently puts it "it's still a problem of the fact that there's this dark curtain and we are on one side of it and the whole world is on the other side of it. This is society." All of the parents discussed their isolation as illustrated in the following quote:

Because you can get very isolated, very easily….Because people, you know, people don't understand, you know, uh, people who don't live, who don't have kids with the chronic illness, uh, just don't understand it at all. That's really hard (Susan)

Several of the participants explained that their isolation was somewhat self imposed as described in the following excerpt:

> I basically have no friends. And that's, that's (sigh) really because of choice I think. I think I have isolated myself. I mean, for one thing, I don't have time to have a friend, another is, I don't want to have to explain everything. And then again, you know, I get angry; other, other parents, they can take their kids to soccer, they get to go to basketball, or cheerleading, and I didn't get any of that. So I just close myself off. I guess it's just easier that way. (Stacey)

Other aspects of loneliness were illuminated by the parents' words. Some talked about how it was hard to get the same investment from their spouses "because they had not been in it for the long haul", or, "my husband, he and his mom they don't believe in mental illness they believe it's a crutch to get what you want which, you know, I have to respect that but I feel like I'm by myself." Several of the biological parents talked of protecting their aging parents from the stress of caring for the children even if they were offered support and understanding. Two of the men in the study described feeling lonely for their wives and friends:

> Sometimes I need to talk to another guy, or, you know, my wife is spending so much time with this kid, she don't care about me no more, type deal. Then, then, I'm sure she has the same problems, my husbands going this, that and the other, not caring about me no more - too much involved with the kids. And sometimes we just need to have time by ourselves that we can, just me and her do things with each other, have time, own time. (Chuck)

"And So It Was All My fault"

Contributing to their loneliness is the fact that they often feel degraded, humiliated and blamed. The parents describe how their loneliness is made even more painful because others imply that they are somehow to blame, whether it is because of being a poor parent, somehow being responsible for bringing the illness upon their child by genetic illnesses, or marrying the wrong person. As Stacey said, "and so it was all my fault, I should have protected her." There were instances of feeling blamed in all of the transcripts as exemplified by the following quote:

> And if you go in to talk to the psychiatrist, it's almost like "Are you giving medicine to this child, or are taking it for yourself?" And then you get the state coming back - you know, they're saying you've got a child that's being disruptive at school, disruptive at home, maybe you're the problem here, you are going over asking for drugs for this child, maybe it's child abuse. You know maybe it's something you're doing; maybe we need to investigate you. (Peggy)

This blame is degrading and humiliating to the parents, as Stacey explains, "Yes, I feel like sometimes, I'm treated like a, uh, like white trash. Like we may see this white trash 'cause look at how your kid is or ah, or ah, you know, how did you raise her? Or even then when I say. 'Well her dad was diagnosed with schizophrenia', 'well, how did you get with him'?" It is very degrading to Tricia when she takes the initiative to give the school information about a new medication and she is met with disinterest, " you know, I have to let the administrators know that this is, what it's from, and half the time they just look at me like (blank look, SIGH), and they just look at me. I get the blank look."

The times when they do feel understood are met with emotional relief and often tears. Again, Tricia summed it up when she talked about finding an empathetic psychologist, "and uh,

that's the first time I thought, like, Uh, somebody understands. Oh my God!" Describing times when she received positive praise brought tears to Peggy's eyes:

> Every now and then, someone will come to me say "You're doing a good job". But there ain't nobody else out there for them. We just has to be strong until we learn this is the way it's going to be, and if you don't like it, if you want to send me to jail fine, and if you don't like the way I do things fine, but this is the way it's gonna be and you're not gonna hurt that child - that child has already been hurt enough. And I'm going to do what ever it takes. I'm sorry (crying) it does get emotional. (Peggy)

"Shunned Away"

One of the most painful aspects of feeling alone, related by all of the parents, was that they or their child was "shunned away." This includes feelings of alienation from traditional family and societal activities such as going to restaurants, their child being thought of as "the other", and deliberate and cruel expulsion from general society. All of the participants described incidences of their child being regarded in a negative light or excluded. They talk about how their children have been called "freaks", "bad", "devils", or "the other", and how they have been "outcast", "kicked out" and "shunned away", and received "unmerciless teasing." The children ask, "Why don't you like me?" and "Why can't I play with you?" and get the answer, "I don't want to hang around with a freak." One recalled a horrific occasion with a dentist:

> He's like, "I don't see children like this." I said, what are you talking about?" He said, "I don't see children like this." He goes, "You need to get her and take her to somebody that can deal with this." And I said, "Deal with this", I said, "she's just a kid and she's afraid."

> And uh, he was like, "Get her out of here", "Get her out of here." Right in front of my daughter and the nurse. And the nurse, she took up for me. I mean, I was surprised because I'm not used to that. But she said, "Well, she can't help it; she's just afraid." He said, "I don't care; I'm not dealing with this." And he walked off. And so I'm like what am I supposed to do. You know. I took her to the one dentist that was accepting new patients that took my insurance in the whole town I lived in, at the time. (Stacey)

The rejection of their children was described as being intensely painful by all of the parents, they experienced stigma, and were very aware of the child's hurt feelings and how society does not always accept that the child's condition is an illness:

> It hurts me to see that my grandson has to go through being kind of put, shunned away. I'm, I'm, nobody should have to be, you know, shunned away, I don't want to see anyone shunned away, shunned away, everybody should be treated good and be popular and human beings. Because you have a disease is not no reason to shun people away. That does happen lots and lots. (Chuck)

Many participants talked about a slow reintroduction of themselves into society since the diagnosis. However, this progress was slow and tentative because of past uncomfortable experiences:

> It's very exciting, we've actually had some family outings when we went to the park, that's just in the past month, before we would be lucky to go out without a scene. So it

was just something you just avoid. You do what you can to stay home as much as possible. (Stacey)

"I Need Help"

Consequent to feeling alone, the parents expressed a strong desire for help. They talked about "having no place to turn", that "what they really need is help," Tricia expressed it" I just, I don't, I don't know, I very much don't know what to do anymore. I just really don't, you know," Similar emotions were expressed by all of the other participants:

> I had no place to turn - no place to turn, and he was so out of control, his medicine was so bad at that time me and my husband slept in shifts - he would tell us that he would kill us if we slept. Not wanting to see this child go back into a mental institution, not wanting to see this child picked up by the police department and all this time, the counselors, meaning well, saying, "If he goes out of control, unless you're qualified, you better not restrain him, because if you put a bruise on him, I don't care if he is trying to kill himself, if you try to stop him and bruise him, you can go to jail for child abuse," And I thought it's a no win situation. It's no win; we're trying to save this child's life and these people, instead of helping us, you know, they're going against us. And I need their help, I need their cooperation, I need them to follow through with what I'm doing. (Peggy)
>
> All of the participants voiced their desire for more education from health professionals.

Tricia remarked, "got her in to see a psychiatrist, and the lady would never, it was just, 'Yes, she's got a mental disorder.' Well, what? I mean, there's different ones out there, which one is it? Every time I talk to her, it was like up this medication, take her off this one, do this one. I

never could get an explanation out of her." John also recognized his need for education, "I really need to learn a lot about it. I mean, I would like to have a better understanding of everything, you know, different ways to cope with it different ways to deal with it different ways of, I don't know, punishment, theory, different aspects of it. You know, what something goes on, what everything." And Tricia again sums it up " and I'm in a situation where I have to figure out how to uh, work, take care of her, uh, be assured that she gets every thing she needs, give her everything she needs, but I can't do all that enough, because what I need right now is help."

"I Cry so Many Tears on This Child: It Hurts, But it's Worth it"

All of the parents expressed that they felt hurt at times. The strongest emotional hurt was expressed as the inability to fix the illness and the pain that the illness inflicted on their child. Susan said, "Well, it hurts because you just can't pick up and go. It hurts because you know it's not really their fault. They don't want to be like that, you know. And it hurts because you can't fix it. That's a really big one, you can't fix it. There's no magic pill. You can't wave a magic wand and make it all better." The following quote is an example of the hurt and sadness:

> Uhhh, I just shudder. It, it pains me to think that, uh, she may have to go through some of this. Uh, but see, even under control you do have these mood swings and uh, it really bothers me that she's not going to have what you would call a normal childhood. I mean, her previous experience is abnormal and this is abnormal and uh, it's a, I just really, really feel sorry for her. Uh, it's not fair to her. Uh, it's a, she's been cheated somewhat. And there's nothing I can do about it. (Steve)

Many parents described times of intense anguish. Stacey richly described her feelings

related to the exorcism, "That [exorcism] was very draining; it was very, very draining emotionally. Because to, to know how much I had, at that point, how much I depended on God to get me through every day, you know prayer, and just, you know praying that God's not going to give me more than I can bear." She also talked about having to restrain her child, "I'm usually crying along with her, it breaks my heart to have to do it."

All of the grandparents were hurt by their loss of traditional grandparent role "I can't be the grandparent, that hurts too."

> Well that I was robbed of being a grandmother, that I can no longer be the grandmother any more - I've become the caregiver. So I have to take the place of a grandparent, a parent, a teacher, a caregiver, nurse, psychiatrist, lawmaker, and its, well we should be thinking of enjoying retirement and looking forward to retirement, and all this has been taken away from me. It was a very hard thing for me to deal with (Peggy).

The physical hurt was primarily described as exhaustion although many of the parents gave a history of stress, physical and emotional illnesses, and physical attacks on them by their child. Examples of exhaustion are, "I have no energy. Sometimes I wonder if I'll ever feel rested again, constantly readjusting, and that's exhausting; "and she's to where she's very little sleep, so whatever you do it's that much harder, very little sleep, very little, very little, I've been there"; "I feel like I'm frazzled, not just today, but always." The physical attacks by the child were common and extremely stressful, "he's hit me; I've carried bruises."

For the grandparents especially, the loss of peace was difficult as evident by the following quote from Steve, "Uh, the negatives are that the biggest thing with them is there is no quiet in this house until she goes to school and goes to bed. I mean, there's no quiet in this house,

I'd like to be like my dad and just take out my hearing aid. But, can't do that. Actually, that's the biggest negative, is the amount of activity that they generate, I'm sixty years old for crying out loud." However the grandparents said "the positives outweigh the negatives" and that having the children had improved their wellbeing. Chuck felt physically healthier, "Actually, I've gotten more healthier, because I have to work with these children. Like I say, I'd just sit around the house doing nothing, watching TV, do what grandparents do."

Nevertheless, even though the experience is often painful a sense of commitment and hope pervaded the parents' stories. Many used the phrase "It's worth it." Worth it because of the "hugs and kisses" from the child, moments of normality, success in finding good care, the ability to reach out and help others, the opportunity to help the child that they love, and hope and faith in scientific discoveries. Love expressed to and by the child was described as being tremendously reassuring to the parents often called a "blessing.' As Peggy states "Every day…It has its problems but it also has its rewards." The researcher did not find any expressions of resentment. All of the parents talked with love about their child:

> I tell him continuously, "I love you," this is the reason for it. His therapist asked him the other day if nobody else loved you, who do you know that you've got? He said, "I've got my mom." And that makes me feel good, so… (Sarah)

> And there is times, when, like I said, it could go bad for a long time, and then the child will come back to me, maybe days later, and he'll hug me and he said, "Mammaw, I love you, you're my best friend." And you know what I think; well this is worth this. I'm sorry, I didn't mean to…. It does get emotional. (Peggy)

> And I let my daughter know every day. I'm extremely grateful that she's in my life. She is my, going to my heck of a roller coaster ride. But she's definitely worth it. (Tricia)

> That's what I get out of it. I get "I love you" or a hug or a kiss and that's worth way more than money. You can take your money and spend it and it's gone but I can take "I love you" to the grave with me, and even beyond, I don't know. (Chuck)

The intelligence and the potential of the child particularly raised the hopes of the grandfathers as revealed by the following quote:

> So we need to be careful, but yet we have the opportunity, great opportunity, many of these children that, you know, we could be raising super kids, all of them could be uh, presidents or scientist or like Buzz Armstrong, he's bipolar. There are so many people who are bipolar that have, can still make a great uh, difference in, difference in life. Maybe the next great pharmacist, you know. (Chuck)

Comfort comes in other ways such as "little tricks", work, or faith, "yes there's someone higher in control, someone who's listening and prayer is getting it answered", or "I believe that there is a being greater than myself that loves me no matter what I do, or how I am." Sarah explained, "what I call my other life, you know, work. I mean, that's a kind of get away from it. But I'm blessed, very blessed. And that keeps me at my job. That, and loving what I do and the people I work with, too." This is true for Susan, "at night after the kids are in bed. Ooooooooooh! Those are really nice, and when the kids are in school, it's like OK, I can work and just work, work is good."

The sense of personal growth and empowerment is also comforting to many of the parents. Chuck sees new opportunities, "I've got a second chance to, I've got the opportunity to fix the mistakes, as I raised my kids, you know, I've made mistakes there and I try to look back and look on those mistakes and try to change it and do better for these boys than what we did for our own children." When Tricia talked about getting further education in social work in order to help others her face lit up as she said, "It's made me a stronger person definitely, And since this has all come about, It's like, You know what, I need to go, and I need to get my, my education in uh, social work, and I need to go and I need to get with the schools and I need to hold and give seminars or whatever and get them to understand these students." With strength she now says, "I can handle it. Talk to me about it."

Even in the midst of this powerful demanding experience many of the parents expressed satisfaction in "being a huge advocate", and reaching out to help others. As Chuck said "You've got a big wide door there and I'd like to do a bit to close it."

> Reach one, teach one, you know. Well, it does too, you know, I think about it, you know, every time I teach someone helps. You don't know who you're helping because they may some day down the road, run across somebody and help somebody else. They may overhear someone, "Why no, Bipolar's actually a chemical imbalance in the brain, you know." You know, and save somebody else that way, you know. (Susan)

Through her tears Peggy described her support group:

> No, I'm fine. I kinda' do this daily (Cry). That's one of the things that when we were, you know, getting our support group, Uh, we keep plenty of Kleenex tissues laying around for

> when one cry, we're all crying, because we're feeling for this person. We're going through the same thing; we can appreciate what this person is going through. And I think that is one of the things… there never was a support group in this area until we started one. (Peggy)

Better education, finding a good doctor or school, and belief in the genetic and biological component of the illness were all sources of hope for the parents. They all talked of finding hope in the possibility of future diagnosis, techniques, treatment, and cure. The flowing quotes describe this hope:

> but eventually I keep hoping by the time my children have children you have the little machine and you just put DNA samples, blood sample in there, and they'll be able to pop out and say exactly which medication will fix the problem. I'm really hoping. (Susan)

> "the new gene therapy - this excites me, you know, I'm thinking this is a possibility down the road, this could be, for him, down the road. This could be the end of all mental illnesses that we're seeing (Peggy).

Summary

The findings as described were gleaned from in depth face to face phenomenological interviews. Four themes stood out as distinctive, which must be understood against the contextual ground of others, primarily the child and professionals in the educational and health systems. For the parents in this study if you are a parent of a young child with Bipolar Disorder it means that you will experience unrelentless fear, frustration, loneliness, and hurt. You will spend every hour

of every day in chaos and uncertainty and many hours managing the demands of the illness and inadequacies of the system. You and your child will experience stigma and rejection. You will need to be strong, to fight for your rights, and to educate yourself and others, including professionals. However, the child, the prime consideration of your life, will make it all worth while. The following chapter addresses implications of the findings of the study for nursing theory, research, and clinical practice.

CHAPTER V

DISCUSSION

"and if I was a flyer who fell now and then, you'd pick up the pieces and fly me again"

(Coulter, 2003)

Introduction

The purpose of this study was to examine the meaning of parenting a school age child with Bipolar Disorder. Ten parents were interviewed using an existential phenomenological approach. The parent's narratives revealed four themes as discussed in the previous chapter, (1) *"it's always, always: engulfed in chaos";* (2) *"my hands are tied: scared and frustrated"*; (3) *"on the other side of a dark curtain: alone and shunned away"*; and (4) *"I cry so many tears on this child: it hurts but it's worth it."* This chapter further explores the meaning of the experience in relation to theory and past research. In addition, implications for nursing practice, education, and research are discussed.

Contextual Ground

The ground against which the parents in this study experience the phenomenon of parenting is others. This ground shifts unpredictably back and forth from the child to others in the larger world. This shifting perspective may be understood in the light of the parents' close bond with the child. As the child shifts from illness in the foreground to wellness in the foreground, described in Patterson's (2000) shifting perspective of chronic illness model, the parents' tasks shift from dealing with the child's crises to dealing with others in society and the health and educational systems. Christian (1998) calls this "shifting gears," whereby the parents respond to

the children's condition with intensified normal parenting roles of advocacy, caregiving, protecting, and nurturing. For the parents in the current study there was no respite because the shift meant that their energy was redirected to dealing with the system. It is not known what significance this continual shifting has on the parent's ability to adhere to behavior modification, positive parenting strategies, or self management of their health.

It is important to remember that while the parents were helping their child develop they also were striving to complete their own developmental tasks and roles. With children in this age group it is the parent's role to help their children thrive, by promoting their independence, getting them ready to move in and out of the family system (such going to school, sleepovers, and team sports), and helping them assume more responsibility for managing their symptoms. Faced with the non normative task of raising a child with Bipolar Disorder, the parents in this study are trying to come to terms with the unexpected life situation that has come their way. As explained in Pollio, Henley, and Thompson, (1997), Heidegger (1927/1962) talks about the concept of thrownness: "human existence is always Geworfen (thrown or cast from the German *zuwarfin* to throw), it comes upon itself in a middle of a situation, and has to assume its own future". (p.102). Being thrown into this parenting situation has altered the participants' personal and family development life cycles and relationships, leading to family disruption. According to Lantz (1999), Heidegger's position is that human beings can react to this "thrownness" in one of two ways, "arrogance" where the person acts as if he or she is the center of the universe or "brightness" where the person manifests love and caring. The parents in this study consistently reacted to their thrownness with the latter response of love and caring, as demonstrated by Tricia who said, "and I let my daughter know every day, I'm extremely grateful that she's in my life."

As discussed in Chapter IV the parents in this study exist in a state of disruption and chaos. These findings are consistent with Garwick et al.'s (2002) findings that having a

preadolescent with a chronic illness leads to family disruption, emotional strain and financial burden. In addition, it lends support to research by Norbeck et al (1991) who found that the family reorganizes their lives around the care of the sick individual. As described in Chapter I, studies have identified that parents of a child with a psychiatric illness have tasks that include maintaining a sense of self and hope. Although maintaining hope was evident in the participants, they disclosed clearly that they had lost a sense of self. This loss of self has health implications for the parents. If the experience is not transitory, loss of self may itself lead to feelings of a chaotic and unpredictable world, sometimes leading to overwhelming anxiety. The ability to maintain a cohesive sense of self is dependent on the presence of familiar anchors; in the absence of these anchors periods of unknown dread may break through (Pollio, Henley, & Thompson, 1997). As Stacey said, "I'll become overwhelmed because, oh my goodness, look at what I've had to deal with, and then I start thinking, oh my goodness, what am I going to have to do!"

Themes

"It's Always, Always: Engulfed in Chaos"

This theme describes what is figural to the parents in terms of time. The parents described how this immense task of parenting consumed all of their time, from minute to minute reaching into year to year. They also experienced time as chaotic and unplanned. For these parents, time is an embodied experienced, felt as engulfing and suffocating; something that surrounds them with uncomfortable feelings. Merleau Ponty explained (1962), "I am not in space or time, nor do I conceive space and time. I belong to them; my body combines with them and includes them" (p.140).

Dapkus-Chapman (1985) conducted a phenomenological exploration of the meaning of time, which fell into four themes: change and continuity, limits and choices, now or never, and

fast and slow. When viewing the participant's experience in terms of Dapkus-Chapman's (1985) thematic structure, it becomes clear why time, for these parents, is out of synchrony, that there is a lack of continuity to their lives. Most of us struggle with choosing how we will use our time and are limited by forces such as work or interruptions. We often get frustrated if our plans are thwarted. For the parents in this study choice is very limited. Many of the parents talked about not being able to plan. Susan described her frustration:

> There have been times I've not been able to go some place because the kids are just being too much. And that hurts, and it's hard, and it makes me want to throw things. I wish I had a big pile of crockery and a wall and just throw things. (Susan)

According to Dapkus (1985), we also experience time as "now or never", relating to feeling an urgency to get what we want in case we never get it. The parents in this study also felt this same urgency as they talked about the future and impending adolescence. They were stressed, feeling pressured to get adequate treatment in place. Tricia talked about how she thought about her 8 year old daughter's upcoming adolescent years:

> I know I shouldn't do that, I should just take it one day at a time, but I keep thinking, Oh my God, if this is stressful now, what's it going to be like when the hormones are changing and the chemicals in her body are changing, and her brain is changing? It's like, Oh my God, OK, so when she's an adult, you know, she's going to have to deal with this on her own. And then I look at the, uh, possibility of her not living to be an adult. I can't think about that because if I think about that, I'll be constantly worried. (Tricia)

The last theme that emerged in Dapkus-Chapman's (1985) study was tempo, "fast and slow". In traumatic events such as a car accident, clock and personal time are often out of synchrony; time is often said to slow down (Pollio, Henley, & Thompson, 1997). The type of experiences that the parents in this study endure, such as violent attacks from their child, school suspensions, police and child welfare agency involvement, and bizarre frightening behavior, would reach crisis proportions even if taken in isolation. For the parents in this study there is no beginning or end to these events. Recall the participants talking about the experience being "all encompassing, and engulfing." Merleau-Ponty (1962) wrote about this experience of time "it is being encompassed, being in a situation prior to which we did not exist, which we are perpetually resuming, which is constitutive of us" (p.427). This has implications for the psychological health of the parents as mature defense mechanisms can regress temporarily in periods of asynchrony, leading to depression, or giving up (Bee, 2000). Psychotherapy can be conceptualized as attempts to repair experiences of chaos or asynchronous temporal rhythms (Pollio, Henley, & Thompson, 1997). Therefore, this study lends support to family focused therapy that includes therapeutic support for the parent as well as the child. None of the parents interviewed was receiving individual psychotherapy. It is unclear if it was ever offered to them except in one case where John stated that he would like counseling but was unable to afford it.

What the parents lacked was being able to locate their development in the natural order of things. Sarah described her uncertainty and inability to feel secure in the normal sequence of events. She talked about it in relation to parenting her other children:

> my expectations of the future … You know, even as parents, we sort of, kind of in our mind, like I've already, the special needs one that I picture her as a young woman still living at home. Maybe holding a part-time job, with a minimal task. That she'll always

be there in my life like that. I picture my oldest one, very bright, moving on and doing other things. I picture my son, and I'm not really sure. I'm not really sure if he's going to be able to handle going to college. Is he going to be able to get a trade? What is his life going to be like after he moves out on his own? What if he doesn't take his medicine? What if he does? You know, all these things go through my mind. So, even though expectations are just expectations, they could turn out totally opposite of what you're dreaming. I guess I have no vision of what things may be like. It's so, just open with him. (Susan)

An orderly temporal perspective is generally considered to be a good thing, correlating with a higher level of achievement and self actualization. A less well developed temporal perspective may be seen in those out of the mainstream (Pollio, Henley, & Thompson, 1997). For parents in non-normative conditions achieving synchrony may seem impossible and asynchrony almost certainly leads to stress. However, it helps us understand the drive towards normalization, a more expected pattern of events, seen in parents with children with chronic illnesses.

Parents of a child with mental illness are very subject to historical forces. Therefore, viewing the parents through the lens of their cohort is very helpful. For example, parents who had their children in the 1970-80's will have a much different perspective than those rearing children in the early 21st Century. Through the years the understanding of the cause of psychiatric illness has moved from a mother blaming perspective to a biological perspective. Nevertheless, being blamed was still very prominent in the experience of the parents in this study.

Notably, parents of children diagnosed with mental illness have to employ different parenting styles from their cohort. For example, it is not recommended to confront an angry or misbehaving child with Bipolar Disorder and rules have to be relaxed and prioritized. These

strategies may not be understood by the cohort that grew up holding the views that consistent authoritarian discipline is necessary for successful child rearing. Parents may encounter judgmental attitudes within their cohort and misunderstanding in the community and among educators and health care providers, also reducing opportunities for social support. This is exemplified by Stacey when she say, "It's the ones that somehow attack me like "haven't you told her no", or "have you tried putting her to bed earlier", or "what are you feeding her", acting as if I'm not a responsible parent."

The experience of "fighting" described by the participants in this study was very reminiscent of Badger's (1996) findings among family members of depressed individuals who described themes of "working the system", as a strategy in "fighting the battle" in order to help their family member. The participants in Badger's (1996) study were also selective in seeking social support because of lack of energy and avoidance of judgment and stigma. Another finding in the Badger (1996) study which was also common to the parents of a child with Bipolar was "maintaining vigilance" (p. 24).

Contrary to Eakes's (1995) study on chronic sorrow in families with adult children with a psychiatric disorder, the parents in this study viewed the diagnosis largely with relief. In Eakes's (1995) study, when the parents first learned of the diagnosis they experienced shock, disbelief, grief, anger, frustration, confusion, and despair. This discrepancy may possibly be a function of the different age groups; the participants in Eakes's (1995) study were parents with adult children and it had been 4-20 years since they received the diagnosis. Most of the children in this study had been diagnosed within the past year. However, this study's participants did describe the same time consuming management responsibilities and poor experiences with health care providers that the Eakes's (1995) study illuminated. The present study gave only partial support to Knafl, et al.'s (1996) findings that families fall into different patterns of thriving, accommodating, enduring,

struggling, and floundering. The parents in this study were enduring and struggling; none were thriving; they were fighting as opposed to accommodating, but they were not yet floundering.

"My Hands are Tied: Scared and Frustrated "

The parents in this study described feeling extremely fearful and frustrated. The health consequences of fear are well documented. The level of arousal that perpetual fear causes is biologically similar to the effects of stress; and the human body cannot withstand it indefinitely. Fear floods the body with epinephrine which affects the cardiovascular system and puts the body on alert. This reaction occurs whether the fear is anticipated or during an actual frightening episode (Karren, Hafen, Smith, & Frandsen, 2002). Frustration is defined as "a feeling that results from interference with one's ability to attain a desired goal or satisfaction" (Anderson, 1998, p.664). This also links up with the theme of "now or never" discussed in the last section. The parents feel thwarted, helpless in the face of the system, and thus experience chronic stress.

Fear permeated all of the parents' experience and their fear is well grounded in fact. They were afraid that lack of sympathy and understanding from those who came into contact with the child in a social or professional capacity would harm the child psychologically. Indeed, it is well documented that low self-esteem is a consequence of being ostracized and that children with Bipolar Disorder are at a higher risk of suicide (Geller & Luby, 1997). The parents were also fearful that their child would harm others and there is a real danger that disorganized thinking and behavior during psychosis or mania may result in the child harming others. Anxiety was very high among these ten parents that they might have the child removed by state agencies or have to give them up in order to get treatment. Dianne recalled such a fear:

> So when he was four he started waking up telling me about these incredible sexual dreams he was having. And I was like freaking out thinking they're going to come take

him from me because they're going to think he's being molested at home and he wasn't. There was no way that he could know what he dreamed from his environment. (Dianne)

This fear of having the state take custody is also well founded. According to a landmark study presented to congress, *"Families on the brink: The impact of ignoring children with serious mental illness"* twenty percent of families surveyed reported having to give up custody of children to the state in exchange for adequate treatment (National Alliance for the Mentally Ill, 2004). In addition, in 2001, 12,700 children were placed in the child welfare system or juvenile justice system for mental health treatment. None had been abused, neglected, or delinquent; the placement was entirely because necessary services were not available in the home communities. Thus the parents in this study were afraid of having to make this heart wrenching decision, which is also hardly a move to a satisfactory therapeutic environment.

The parent who most strongly expressed fear was one of the grandfathers. Along with being fearful for the child, he was also scared for his wife, what would happen if he lost her, and what would happen to them if they lost him. Smith (1996) also exposed a similar theme of fear in siblings living with a diabetic sibling. The siblings talked of having no one to express their fears to, and a fear of death of their brother and sister. These findings suggest that fear is a substantial component of a family member's experience which has not been explored well in the nursing literature. Of note is that the parents did not express a current fear of the child hurting them although some described being afraid before the diagnosis and medication. This was partially because they cared so much about their child, as Stacey said, "I would rather have her hitting me than banging her head on the wall."

Although the parents were obviously burdened in terms of management, finance, and being overloaded, they did not use the term "burden" or report resentment regarding the daily

care or the child. Their resentment was due to the sense of frustration and incompetence in the system that seemingly created a large part of the burden. This finding supports studies that hypothesize that stress may be a result of responses to the impact of burden rather than the burden itself (Fisher, Benson, & Tessler, 1990). The concept of family burden has been well established but studies have not found consistent positive correlation between objective and subjective burden and there has been limited effectiveness of educational interventions on coping (Loukissa, 1995). This is interesting in the light of the current study and Schwartz and Gidron's (2002) findings, described in Chapter II, that high burden was not positively related to low gratification for caregivers. These findings suggest that researchers might take a new look at the concept of burden.

The current study lends strong support for the many studies that demonstrated inadequacies in the health system. The parents in this study were very disappointed with psychiatric care, felt at times degraded and humiliated by health care workers, and were outraged at the lack of knowledge and resources among health professionals. In addition, parents in this study certainly felt blamed, discounted, and frustrated, which is consistent with Faux, et al.'s (1996) findings. The parents also expressed a concern that professionals did not care about their children, which supports Starr et al.'s (2002) findings wherein parents felt that mental health professionals did not care for their child or care about them.

All of the parents voiced wanting to be an equal team member exemplified by Dianne's words, "I want to be an equal, I'm not saying this to be flippant, I think I'm more knowledgeable now. I'd like for them to hear me, I am the mother, I know what's going on." This finding contradicts Kirschbaum & Knafl's (1996) study that postulated that some parents desire a dependent relationship with the health care providers. All of the parents in this study wanted the opportunity to make independent decisions in collaboration with the health care team. This

phenomenon may be a function of the loss of trust evidenced by the parents' narratives. Their experience was similar to the parents in Delaney and Engles- Swans' (1996) study who experienced years of securing services, were struggling to understand the illness, and involved in securing a future for the child and family.

It was very clear in this study that school issues were a great source of frustration for the parents. This was true across the board even though the participants lived in two states and some distance apart. The National Alliance for the Mentally Ill (NAMI, 2004) report to Congress said that teachers do not understand basic facts about mental illness and often continue to blame parents for the child's behavior. This was borne out again and again in the parents descriptions.

"On the Other Side of a Dark Curtain: Alone and Shunned Away"

The parents in this study felt a profound isolation as a result of being placed on the outside of mainstream society. Barrell's (1997) phenomenological exploration on the human experience of feeling alone concluded that there are different ramifications for humans that are dependent on the type of aloneness. The study elucidated the following four themes:

1. Freedom, which included the sub themes of freedom from and freedom to, leading to a state of feeling alone, mostly associated with feelings of contentment.
2. Missing, with sub themes of yearning and emptiness, associated with depression. At times the parents in this study missed who they felt that the child really was, the sweet child buried under the symptoms of the disease. The grandparents missed the opportunity to have traditional grandparenting roles.
3. Barriers, differentiated into sub themes of different and indifferent, which expressed situations where a person feels separated, disconnected and cut off from others. They feel different, out of place, not understood. They also feel that others are indifferent and that they are actively excluded. This was evidenced in the current study by the parents' tales

of being rejected, misunderstood, and marginalized. The parents yearned for times when they could join in social occasions with others without feeling judgment.

4. Vulnerability, with sub themes of unsupported and exposed, associated with anxiety. Vulnerability included being on one's own without support or protection, feeling limited and exposed, unable to realize projects without help and overwhelmed by responsibilities. The parents in this study felt exposed and unprotected, both for themselves and their child; they especially felt defenseless in the face of another person's negative appraisal.

All but one of Barrell's (1988) elements of feeling alone were described by the participants in this study; in fact, they expressed yearning for the freedom to be contentedly alone. Even during the times when they were by themselves, such as when the child was at school, parents were attached to the phone anxiously expecting a call. Such a yearning was described by Peggy:

> I have had days it has been so rough that I've come home, sit down, no cell phone, no TV, and just sit there in the quiet and enjoyed the quiet. And a lot of people think that's strange, how rewarding it was for me, to sit there in peace - - just for a moment. (Peggy)

Participants in Barrell's study made a distinction between the times when they felt alone but not lonely. This feeling is exemplified by the title of the current study *"Crying Alone With My Child"*; the study participants were alone although surrounded by others. They felt alone in a room full of educators, they felt alone in their churches, they felt alone in public restaurants, and some felt alone in their own families.

"I Cry so Many Tears on this Child: It Hurts but it's Worth it"

The parents in this study described feeling hurt, expressed as both emotional anguish and physical exhaustion. The feeling of hurt and pain is understandable when one considers Merriam Webster's (2004) definition of stigma "a mark left by a hot iron, a brand, mark of shame or discredit." However, the pain was definitely worth it for these parents. They refused to give up, found ways to maintain hope, and above all remained clear about their child's underlying goodness, intelligence, and potential. Dianne recalls, "I have cried so many tears on this child because he's actually so incredibly loving and sensitive, and he's truly bright."

Normalization is defined as "minimizing the impact of an impairment and maximizing a child's abilities (Rose & Thomas, 1987, p. 133). According to Rose and Thomas, (1987) "The basis for these efforts comes from a parent's ability to see the child first and the disability second" (p.133). Consequently, the findings in this study are consistent with studies detailed in Chapter II whereby families pursue normalization by developing strategies to minimize the disruption of the illness, avoid potentially embarrassing situations, and celebrate moments of normalcy. Peggy related one such moment:

> TD had his arm around his brother and he had the flash light, holding it so they could see to make it to the house, even though it was daylight, to bring him back into the house. And I'm thinking this is precious, this is Kodak moment, and I was, I cried, I mean, we had normal, we had normal! At that moment, we had normal and it was so precious, these children were able to do that. That we had come to that point. (Peggy)

However, uncertainty poses a threat to normalization and the parents experienced a great deal of uncertainty because of the nature of Bipolar Disorder. Although moments of normalcy

were described with enthusiasm, this study did not support Kearney and Griffin's (2000) study with parents of young disabled children, which resulted in a thematic structure that included "joy." The parents of children with Bipolar Disorder did not experience joy. When requesting feedback the researcher had initially proposed a theme titled "blessings," as many of the participants had used the word and had described things that the researcher had felt were blessings, such as self actualization, the intelligence of the child, and "hugs and kisses." However, this theme was soundly rejected by several of the participants. As Sarah stated, "It is heart wrenching to see my son go through this torment. Blessing is not a word I would use: is being a diabetic a blessing?" The study findings were consistent with Kearney and Griffin's (2000) additional findings that other people were responsible for the parents' isolation, rejection, hurt, anger, and defiance.

The findings also fail to support studies that have found that caregivers experience gratification in their caregiving. For the majority of the participants, having to develop inner strength was seen as a source of frustration, a feeling of being "forced to" by professional inadequacies and societal barriers rather than gratifying. This frustration was described by Stacey. "At times I did feel like I was educating the doctor and I really didn't feel like he knew what he should know about Bipolar Disorder, especially about specific information I was able to find on the scientific web sites." An exception to this was Chuck, the grandfather, who felt that his life had indeed been blessed by the advent of the child and would not have his life any other way, "and I would not trade one minute of what I've been through, and you know it's a blessing to me to be with these kids, these kids have so much bettered my life." This discrepancy may be a function of the differing developmental levels of the older caregiver.

The current study does not support findings described in Chapter II that over time most families are able to find meaning and incorporate illness management into the daily routine so

that family life resumes. When planning their daily routine the parents in this study took steps to reduce their exposure to hurtful social situations, such as Dianne's recollection. "I can remember the thought of going to the grocery store. I would be in tears coming home from work; I don't want to go to the grocery store with my child."

Although the experience was not expressed as joyful or blessed the parents were strong in their conviction that their child was worth all of the hurt. According to Merleau Ponty (1962), we do not have to be passively subjected to time but "it withholds from me what I was about to become and at the same time provides me with the means of grasping myself at a distance and establishing my own reality as myself" (p. 427). These parents are withheld from one life but introduced to another. They are establishing a new reality by educating themselves, fiercely advocating for the child, pursuing moments of normalcy, and appreciating simple ways to find comfort.

Reflections on the Study Findings

There were several additional things that stood out for the researcher as she was immersed in the transcripts and in dialogue with the participants and the phenomenology research group, one of these being the language of the illness. Many of the participants talked about not possessing the language to articulate the manifestations of the symptoms. One such example is when the parents talked about the quieter periods after the irritability and explosions, such as the child falling asleep, headaches, and expressing remorse and shame, "I don't know what to call these things, this I call the aftermath." Tricia described how the language added to her feelings of stigma:

> And its like, uh, suicide. Suicide is this big black word, suicide, you know. Well, you're going to be a disorder, you know, and that's how we got this group of "dis" words, this group of clean words which are OK, cancer, you know, and then you've got this group of black words. Uh, suicide, Uh, depression, drug use, disorder, disability, you know. It's all these black words are over here, that aren't OK, that if it's clean words they are Ok. I didn't think about it until my daughter and, all of a sudden, it's like I see these black words now. She has this disorder; she can apply for disability. They're problem children; no they're not! They're children with a problem. (Tricia)

Words have a meaning and speech is an embodied expression. On the topic of language Merlot Ponty (1962) wrote, "beneath the conceptual meaning of the word is an existential meaning, the spoken word is a gesture and it's meaning a world" (p. 184) and speech is, "a revelation of intimate being and the psychic link which unites us to the world and our fellow man" (p. 168). He gives the example that speaking of anger does not make us merely think of anger, it is anger itself. With physical illnesses objective descriptions of symptoms are freely available to parents such as rash, swelling, or temperature. However, the parents in this study did not have these kinds of words; they resorted to metaphors to describe the symptoms such as "Armageddon", "meltdown", and "going off."

Parents frequently express their frustration at not being able to convince practitioners of the rapid cycling and symptomatology (Geller et al, 1995). The confusion expressed by parents (such as normal parenting strategies not working) may interfere with their communication with the psychiatrist and could explain why parents perceive that the doctor is not listening to them. It is incumbent on nurses to help parents to use a descriptive taxonomy and to avoid perpetuating the violence by using violent terminology. They can teach parents and educators the appropriate

medical terminology, and be aware that some of these episodes can also be associated with a greater social competence and popularity. Terms such as verbal fluency, enhanced motivation, sharpened thinking, fatigue, flight of ideas, goal directed activity, and increased motor activity, are less stigmatizing.

Although this is a small sample, with only three males, the findings in this study are consistent with Knafl and Zoeller's (2000) findings that male and female responses do differ. The male participants talked about feeling incompetent in illness management, saying they would not know what to do without the female partner. The men also expressed more confusion. Although the men were actively involved in illness management and daily routine the women did most of the research into the illness and educational laws. These findings highlight a need for more research in this area.

This study was generally more consistent with studies of parents of children with chronic physical conditions than those of parents of adult mentally ill children. Notably the study strongly supported Nelson's (2002) metasynthesis of mothering other than normal children (predominantly with chronic physical conditions) which was discussed in Chapter II. In accordance with Nelson's (2002) findings the parents in the current study experienced a learning curve in relation to negotiating relationships with the family, social, healthcare and educational systems and they were dealing with a family life that will never be the same. They also experienced caregiver burden (although they did not call it a burden) related to alteration in roles, and isolation. They certainly experienced avoidance of others, uncertainty, the significance of normalcy, looked for signs, grieved loss of a normal child, and the embrace of paradox (the compromise between acceptance and denial).

Implications for Theory

This section of the chapter reviews the suitability of the existential phenomenological method for the problem and discusses two theories that may be useful to better understand the findings, Bronfenbrenner's (1979) ecological theory and Baier's (1986) theory of trust. The researcher supports the use of the phenomenological framework for psychiatric and chronic illness research. The method used at the University of Tennessee uses a multidisciplinary interpretive group including social workers, psychologists, and educators, which added balance and understanding to the researcher's understanding of the parents' experience. The researcher's experience supports Munhall's (1994) position that phenomenology is a caring approach. The participants in the study reported feeling better after the opportunity to talk freely and at length. They willingly provided feedback and expressed great interest in being regarded as co-researchers.

Ecological Theory

It was evident to the researcher that a theory to underpin the findings of this study must be comprehensive, transactional, and integrative, as both family and larger societal factors and interactions were figural in the parents' experience. These families were affected by the historical context and were in constant reciprocal interaction with multiple systems. Therefore this complexity requires a theory that takes into account the context of the world in which we live, and the state of the social, cultural, and political systems with which we are negotiating.

The ecology of human development theory was first proposed by Urie Bronfenbrenner (1979) with the basic premise that human development is a product of interaction between developing persons and their environment. He later made modifications to the theory which included designating the family as the context in which development occurs. Bronfenbrenner's (1986) perspective is that it is meaningless to interpret a family's behavior apart from contextual

influences. Bronfenbrenner's (1979) ecological theory holds that as the individual is nested within the family, so too the family is nested within the community, environment, and social and political system. The theory is conceptualized as interrelated systems:

1. The ontogenetic system, whereby each individual brings characteristics and behaviors that affect the whole family. For the family with a child with Bipolar Disorder this would include the genetic components and prior experiences of the parents.
2. The microsystem, where roles and interpersonal relationships in the family occur in the immediate setting. For the families in this study these would include the home, schools, and workplaces.
3. The mesosystem where family interactions intersect between two or more settings such as school and healthcare.
4. The exosystem, which refers to settings that affect individual or family, which, although not involving them as an active participant, may affect them, such as state systems of care or health insurance programs.
5. The macrosystem which refers to the overarching general influences that directly affect the individual or family such as culture, education, economies, ethnicity, or religion. Here the families are affected by cultural views of psychiatric illness, such as living in a country that does not celebrate difference or eccentricity, and where stigma and prejudice remain social and political issues.
6. The chronosystem, which refers to changes over time in the individual, family, and environment such as life transitions (classified as normative and non normative) and development in the larger world, such as knowledge, or large system evolution, such as civil rights laws. Applicable factors are the move to deinstitutionalization of mentally ill

individuals and increasing attention by world health organizations on the disabling impact of mental illness.

If family mental health is viewed through an ecological lens one can see how it is impacted politically and sociologically by unsympathetic leadership, public opinion, economic hardships, worldwide conditions, and lack of health care. As used in many family nursing studies, Bronfenbrenner's (1986) theory is applicable to nursing practice and this study as an encompassing framework because it includes the biopsychosocial nature of Bipolar Disorder. The researcher believes that nursing holds a role in addressing everything that impacts our clients, not merely caring about the immediate problem confronting the sick individual.

Baier's Theory of Trust

The findings in the current study illuminated a severe lack of trust in the health care and educational professionals that had evolved over many years of frustration and disappointment. Baier's (1986) work on the concept of trust may be used as a foundation for understanding the parents' lack of trust. It also demonstrates why nurses should be acutely aware of their responsibilities in maintaining trust. The concept of trust is an elusive thing that we are so familiar with that we scarcely notice its presence. Baier's (1986) theory combines the moral insights of women and men by integrating the ethics of care and justice. The ethic of care is nurturing of self and others, the alleviation of hurt and suffering, and the maintenance of relationships. The ethic of justice is the rules, principles, duties and obligations for self and society, and fairness and reciprocity. Because parents often build their lives around caring relationships such as looking after children and elderly relatives, Baier (1986) hypothesized that they would need a trust ethics based on both love and obligation. Within the concept of love we expect that we can trust others not to harm us. Within the concept of obligation we expect that we

can trust others to recognize and fulfill their obligations. Bearing this in mind it is clear why the parents in this study lacked trust in professionals.

There are several principles of Baier's (1986) theory, which describe the complexity of trust relationships: (1) there is a potential for oppression and other harm in a trusting relationship therefore trust is not always a good thing to be preserved, (2) trust relationships should be continually evaluated, (3) vulnerability is always experienced when relying on another's goodwill, (4) trusting involves giving another the opportunity to harm but having the confidence that they will not, (5) all of us need others to help us look after the things that we care about, and (6) competence and expertise leads to trust.

According to Baier (1986) innocent trust is very easily betrayed in networks such as schools and healthcare. This may be the result of organizational factors as well as personal factors. For example, trust could become compromised in nursing by difficulties experienced with financial constraints, and organizational policies. According to Baier (1986) trust comes in webs, not in single strands, and disrupting one strand often rips apart whole webs. This was very evident in this study as repeated episodes of failure to respond to the parents' trust resulted in a general lack of trust for all systems of care.

This study supports Baier's (1994) stance that power differences such as seen in the medical model are not always justified. However, according to the theory, power differences can often be rectified with increased knowledge, and when power differences are diminished there is less vulnerability in trust. Thus, the parents' endeavor to educate themselves and thus, the need for educational components in interventions. Baier (1994) also has a lot to say about people in the medical and caring professions. She writes that nurses are in a good position to do harm as well as good, and that trust in professionals such as nurses involves the additional element of

reliance on expert knowledge and trust that they will use this knowledge in the interest of the one being cared for.

Using this theory as a suggested conceptual framework for future research into the interpersonal relationship between parent and mental health professionals may hold the key to more successful treatment plans for the child. Baier (1986) emphasized that effort should be made to diminish power relationships and speaks of "judging what should count as failing to meet trust, either through incompetence, negligence, or ill will" (p. 238). A study which is relevant to this discussion is Delaney and Engles-Scianna's (1996) study, which explored parents' perceptions of psychiatric needs. The parents discussed the concept of "failing up" where they described that they felt a need to hurry through the process so that they could get effective treatment for the child. They spoke of having a lack of trust in professionals who changed diagnosis yearly and gave counseling and drugs with limited effectiveness. This was supported by findings in the current study, which make it clear how a professional's attitude and competence are strong factors in establishing the trust necessary for a successful parent/provider relationship. The following quote describes a story familiar to all of the participants:

> Well, we went every where, all over this city, I even had an appointment in another city, which I eventually cancelled, I got a psychologist here and a psychiatrist here, and they, the psychiatrist immediately put him on (a stimulant) in spite of the family history, "I think he has bipolar but its too hard to identify and that's supposedly a good stop gap measure". My response was, from what I have read if you get a child on these stimulants and they're bipolar you can create a big headache, so finally, I just gave up. I can not stand psychiatrists; I can't. They don't hear you. They're insensitive, and all they do is throw pills at you and send you on your way for a month. (Dianne)

This section provided a discussion of theories that might be used to underpin the findings of this study. Both of the theories are well suited for cross-disciplinary use with language understood by both medical and social /psychological professions. Although the parents demonstrated considerable strength it is difficult for the researcher to envision appropriate interventions for them based on the resilience, adaptation, and coping theories. It would seem that barriers to adaptation are insurmountable without intervention in all the contributory factors to their success. Therefore, a theory that depends on the use of support from these systems does not seem to be a good fit. Helping professionals must build the capacity of systems first, understand and meet the parent where they are in their own developmental trajectory, and especially build trust. Adaptation may be an unrealistic goal in the face of such barriers and these parents may need new models of continuous support.

Implications for Nursing Practice

The most significant finding for nursing in this study was the absence of the nurse from the parents' figural experience. Although the children were suffering with a severe chronic illness in the context of schools, clinics, and hospitals, the nurse was invisible to the parents. The parents were also involved in workplaces and churches, but there was no mention of occupational nurses or parish nurses. A nurse was mentioned three times only. Once a parent spoke of a dental nurse who was perceived as supportive, another time, when talking about protecting her child from unnecessary information being requested by educators, Sarah said, "But Dr. Joe's nurse told me that even if I signed millions of those papers, they don't give you any information unless I sign their actual paperwork for confidentiality. And I like that. That makes me feel like they're protecting to me." Thirdly, recall Stacey's visit when the psychiatrist told her to take her child to the emergency room, "But of course, the nurse was doing the intake part asking the questions and

I could tell he didn't believe a word I said, I felt if I revealed too much they would put me in a straightjacket."

This absence of the nurses is even more significant when viewed with the knowledge that both states in which the study took place certify Psychiatric, Community, and Family Nurse Practitioners. Nurses are the only professionals that encounter the child and parents in all these facets of healthcare and society and have a great opportunity to impact families' lives both negatively and positively. With the scarcity of child psychiatrists it is even more important that nurses are a strong visible force for good in the parents' lives. They may also conduct screening and provide family counseling and treatment. All nurses have a crucial role in education, promoting public awareness, and advocating for cost effective mental health care.

The parent needs to be recognized and treated as an equal valuable partner in the assessment and treatment plan. Including the parent as a team member is likely to raise their sense of perceived control. Those with a stronger sense of control are less likely to become physically ill (Bee, 2000). Family Nurse Practitioners and Psychiatric Nurse Practitioners have a strong educational grounding in the family and espouse holistic values that could be very helpful to the parents. A family nursing perspective is the obvious choice to the researcher with no boundaries between caring for the child and caring for the parents. These parents were necessarily enmeshed with their child "there is no one else for them." Clearly, the emotional, mental, and physical health of the parents will affect the child's growth and development, health, and quality of life.

This study elucidates the importance of nurses to pay attention to their attitudes and consider changing their belief system to see strengths rather than problems in children and families and move towards an affirmation model of disability. For the parents in this study affirmation was likely to be denied. This may be understandable if one considers the ample

evidence that denial is widely viewed as maladaptive among clinicians. According to Russell (1993) health professionals should be cognizant of the fact that they may be asking their clients to be "unrealistically realistic" (p. 938). It was implicit in the transcripts that a certain amount of denial was protective to the parents, supporting Russell's suggestion that denial lowers anxiety and protects self concept. Recall Steve's comment, "and in some cases uh, given certain circumstances, you could end up with a Mozart, Edgar Allen Poe, uh, people like that. I mean, they were all part of this category." The parents were hoping for and experiencing positive change, especially after the diagnosis and effective treatment. They expected this same proactive, hopeful attitude from the teachers and the health professionals as the following quote explains:

> It doesn't help when we have psychiatrists and other people tell us that because he was diagnosed at an early age, that he has an 80% or greater chance of either being a drug addict, an alcoholic, or taking his own life by the time he reaches the age of 18, and I live with that thought everyday, everyday. (Peggy)

Nursing interventions that increase self-efficacy by reducing fear and frustration are likely to result in improved outcomes. A strong sense of parenting efficacy has been shown to buffer the effects of other risk factors (Schroeder & Gordon, 2002). These parents demonstrated many of the qualities needed to increase resilience in the child and possessed components of optimal parenting such as responsive parenting, high nurturance, consistent discipline, and high expectations (Siegel, 1999). In addition, the parents in this study, when faced with a huge task are not backing away from their responsibilities, and neither should nurses. By addressing the micro and the macrosystem nurses can make a conscientious effort to develop and maintain a sense of

community for families. This community is shaped by daily experiences of feeling welcomed, supported, nurtured, respected, liked, and valued.

This study provides support for early diagnosis and screening for suicidal behavior and mood disorders for children struggling in school; although screening without services is controversial. The majority of children with depression do not come to the attention of mental health professionals (Wu et al., 2001) so nurses may be the first health professionals to learn of the problem. Assessment strategies should take into account contextual influences, as the same behavior in one context may be adaptive in another. All of the biological parents in this study felt that their children had experienced symptoms from a very young age. These symptoms, occurring at such an early stage of development without intervention, affect the parent child relationship because depression is associated with a decreased capacity to perceive the emotions of others (Rubinow & Post, 1992). The parents in this study expressed great joy at the child's ability to express love and affection when they were titrated well on medication. Like the mother responding to the infant's first smile they too respond with delight and celebration, leading to more smiles and more reinforcement and more "normal".

The needs of families for information, reassurance, support, and guidance are well known and substantiated by this study. Schroeder and Gordon (2002) recommend that clinicians clearly discuss their understanding of the nature of the illness and treatment options to help the parents and child to begin to trust. Discussion of the prognosis is warranted but should be done very carefully to avoid creating a sense of hopelessness. To be effective parent education programs should focus on both information and parenting techniques and the broader personal needs of family members (Schroeder & Gordon, 2002). The parents interviewed for this study experienced emotional pain, exhaustion, and a feeling that they can never catch up. The anguish expressed

made it clear that there are times when nurses need to step in with in home and out of home respite interventions.

It is evident from the findings that for this group of parents the school system, the mesosystem, was an establishment with a great need for education and a place where parents needed support and advocacy. School based interventions may be the only ones available to some children. Simple interventions from teachers such as temporary reduction in academic demands, support and encouragement, periodic monitoring by use of rating scales, and giving feedback to clinicians can be very effective in reducing stress and crisis. Although the teacher is responsible for educational interventions, it is the responsibility of the nurse to educate teachers about medications and symptom management in the classroom. All too often teachers are left in the classroom having to cope with a severely ill child without a plan for support or medical help. This would not happen with a diabetic or asthmatic child. If a school has a student who has been diagnosed with Bipolar Disorder there should be personnel available, preferably a school nurse who is trained in appropriate intervention, in the same way that the nurse would intervene with a diabetic child experiencing hypoglycemia. It is understandable that teachers may experience confusion when trying to balance the picture of a bouncy laughing child one day with the miserable history of school failure and suspensions. This confusion is not present when they see a child in a wheelchair. Nurses can provide education and strategies for teachers to use such as clinical pathways; the educators should not be responsible for treatment.

The study gives strong support for Advanced Practice Nurses practicing in School Based Health Clinics and school nurses in all schools. Participants in this study were impacted by restrictive polices in the school system that contributed to the parents' difficulties in maintaining care for the child. The parents also seemingly had an ongoing battle with the school system and experienced lack of understanding by the teachers in accommodating for the child's needs. The

case manager or school nurse is at an optimal position to intervene and support the parents in these situations. Nurses must understand the interface between the systems to guide the parents, for example there are protocols in place in school to protect school personnel and students. There are also laws to direct school personnel in providing modifications for a special needs child which nurses should be aware of.

School nurses can make a very valuable contribution to the parents' experience in the school setting and reduce barriers to learning. In the very least, they need to have accurate, up to date, information. Along with facilitating interface with the psychologist and educators, educational interventions with the schoolteachers would be an example of the micro-mesosytem interface. The school nurse can present a balanced viewpoint between behavior and biological, psychological, and behavioral symptoms. The nurse can also advocate, teach the educators non-confrontational approaches and communication strategies, keep a library of resources, and increase their knowledge of drugs and interactions.

Nursing case managers, familiar with community resources, are needed to guide the parents through the maze of educational, insurance, and health issues. To reduce uncertainty and fear the parents need to be informed of expected trajectories and a plan developed. Helping the parent to plan for the future and reducing uncertainty about what to do in specific situations will alleviate the sense of asynchrony which interferes with the parent's development. The case manager, using an ecological perspective, would reduce frustration by collaborating along with the family with the various systems, smoothing the interface between the microsystem of the family and the larger meso and exosystems involved in the care. Brown and Herrick (2002) call for new models of psychiatric health care delivery, citing schools as possible sites that would meet the needs of communities. They state that there is no substitute for skilled providers such as

Advanced Practice Nurses (APN) to care for the psychiatrically ill and recommend that APN's increase their role as case managers.

The parents in this study were in need of nursing interventions to reduce their loneliness. Barrell (1988) suggests interventions be tailored towards the kind of aloneness that the person may be feeling. This may be difficult when faced with multiple types of loneliness but nurses could be aware of this and develop assessments that better provide for interventions to prevent anxiety, depression, and marginalization. Most nursing interventions towards feeling alone focus on the loneliness experienced through living alone or after the death of a loved one, but these parents are experiencing different types of aloneness. Some may be amenable to nursing interventions, such as promotion of social bonding and providing opportunities for enjoyable activities by respite care. Vulnerability may be reduced by teaching the parent how to relate more effectively with people in power.

Connecting the parents with support groups is an example of nurse intervention at the exosystem level. The National Alliance for the Mentally Ill (NAMI, 2004) has chapters in many cities and support groups for parents of adult children with a psychiatric illness. They are starting to extend this support to parents of younger children as awareness and earlier diagnosis improves. Nurses can be very effective as professional advisors and sponsors of these groups. The parents in this study expressed great interest in peer support groups but stressed that it was very difficult to find child care, energy, or time. Non traditional support groups such as telephone, internet or email facilitated by nurses should be investigated. Unfortunately churches were not a source of support to the parents and were more likely to be a source of alienation. Parish nurses might target this problem within a strategy to bring disabled and isolated individuals under the care of faith based organizations. Advocating at local or national levels are examples of nurse interventions at the exosystem and macrosystem levels.

Health and social resources mitigate the negative effects of parenting a child with a disability, but need far outstrips availability. All nurses are aware that there is little room in the medical model approach to the issues of preventive care for parents, such as interventions building on family strengths, or addressing poverty, poor schools, and lack of access. Consequently these efforts will require creating thinking on the part of nurses. During the interviews the parents took care to tell the researcher things that they thought would be useful to them and others in the same situation. These are summarized as early diagnosis, being respected as an equal team member, a continuum across school and health care, home and school based interventions, education to and from providers, and non traditional support groups.

As mentioned previously the findings of this study give partial support for a shift to a resiliency model of care. However, this researcher maintains that it is important to realize that it is the child who is sick, not the family. The parents needed support and education to help them care for the child. The parent's resourcefulness, commitment, and fighting spirit demonstrated many strengths that could be a focus for intervention. Clearly, more efficient organizations and funding will assist providers in providing treatment that is more effective. Along with advocating for policy change, nurses can encourage families to join organizations so interventions can be consumer and family driven.

Implications for Nursing Education

This study lends support to strategies that move Colleges of Nursing away from insularity towards collaboration, in part to prevent nursing knowledge being invisible to others. Seeking cross-disciplinary collaboration is an important breakthrough in nursing knowledge and research but there is presently an underexposure of collaborative techniques in nursing education. Greater interdisciplinary communication is needed in colleges of nursing in order to disseminate nurses'

research, pool resources, and reinforce holistic care principles. One of the parents asked, "Do any other health professionals other than psychiatrists have a course or two on psychiatric disorders or are they so specialized that the holistic view of the patient doesn't matter any more?" The Pew Health Commission report (1995) called for reforms in education of professionals and mandated that we should be competent in working in interdisciplinary teams. The report stated that family/professional collaboration is not an option; it is a necessity. This thinking required a paradigm shift that now, over a decade later, was not evident for the parents in this study who continued to lack continuity of care.

Therefore, nurses need an increase in courses that teach inter-professional collaboration. Herrick, Arbuckle, and Cleas (2002) describe the application of such a course whereby academicians did not dominate the educational team, which included family and community support persons. Family members were selected as faculty and mentors for the students. Named Family Centered Interdisciplinary Practice, the course was developed by faculty and parents of children with severe emotional disturbance and involved student participation in community based experience with families. Broad based linkages in higher education will prepare nurses to work effectively in a multidisciplinary setting. Linkages can occur between schools of nursing, law, pharmacy, medicine, social work.

Implications for Nursing Research.

There is limited experience in interdisciplinary research among nurse researchers and a critical need for nursing research in this area to balance that being done in medicine and psychology. This study supports the need for conceptual studies on the experience of nurse/ parent relationships, and trust. As the future is in collaborative practice we need research that reflects practitioners' work experience and needs. In addition we need to include parents of

children with psychiatric illnesses in chronic illness studies, participatory action research, and family nursing studies. Failure to do so may reinforce the schism between physical and psychiatric health and further alienate the parents. The topics suggested by this study are the impact of blaming on parental resiliency, and the relationships between parental functioning, frustration, uncertainty, trust, and stress. Longitudinal studies are needed, especially on the long term consequences of chronic fear.

This population also should be included in midrange theory testing. The findings in the study support Mishel's (1997) model of uncertainty which postulates that decreasing uncertainty will decrease stress. However, this population has yet to be tested for this concept. Family studies relating to the experience of being a family member of a young child who has Bipolar Disorder, which include the sibling and extended family, need to be conducted.

Few treatments are empirically validated for effectiveness, safety, and practicality (Schroeder & Gordon, 2002). Therefore, the field is wide open for intervention studies such as the effectiveness of nurse facilitated internet and email support groups, nurse home visits, and telephone support. Using an ecological perspective, research and practice in community based interventions can draw from a wide range of disciplines; psychology, sociology, communications, marketing, economics, and political science.

Implications for Health and Public Policy

There are multiple system failures as far as youth are concerned. However, there is much evidence, including this study, which supports the use of family based, multidisciplinary, multi-system models to address the needs of families who are experiencing mental health problems. A failure to receive services can result in comorbidity, and portends the likelihood of increased crime, risky behavior, poor school attendance, impaired cognitive function and poor quality of

life. All of these problems are expensive to the general population in terms of both finance and quality of life (Reasor & Farrell, 2004). However, system change is lagging far behind the evidence.

Although fiscal cutbacks are limiting progress, nurses can impact system change on many levels. System change is driven by fiscal accountability. With outcome research, researchers can identify the relevant policy drivers, develop benchmarks, and provide a direct link between access, cost, and quality. At the clinical practice level nurses should increase their visibility by volunteering to serve on local policy making boards, increasing their appearance in the media, and attending meetings to advocate for the children and families. In addition, they should attend and present at multidisciplinary conferences and join multidisciplinary organizations.

In order to change the thinking to outside the traditional practice box that nurses have worked in for many years we should reduce insularity, especially in our professional organizations by forming joint teams with other professional organizations and encouraging members from other disciplines and other nursing practice areas. Other areas that nurses can use their expertise include committee hearings, floor debates, volunteering as grant evaluators, and securing funding for nurse led projects such as School Based Health Centers.

This topic is especially relevant to both state and federal policies and related to an emerging health policy concern as described in Chapter I. At national, state, and local levels manuscripts such as this should be made available to legislators so that they can be incorporated into formal remarks as evidence to support new bills. Timely publications may be forwarded to advocacy organizations, policy makers, lobbyists, and professional nursing organizations. Nurses should make themselves available as evaluators of current and proposed recipients of funding, and recommend alternatives. The profession can mirror the diligence of the parents by vigilantly looking for areas in proposed acts that are pertinent and communicating expert testimony to the

major stakeholders. The legal system is an area where nurses can be powerful advocates for change such as in full service family court models as described by Raphel (2004). Nurse experts are in an ideal position to provide mental health services for children and affect policy, by partnering with schools, being involved in building capacity, creating mechanisms to fund, and advancing communication, planning, and training.

Conclusion

This study has added to the understanding of the experience of parenting a child with Bipolar Disorder. Prefacing this chapter is a quote from an Irish ballad, which tells the story of a mother who picks up the pieces of her children's lives and helps them to "fly again." Dianne was such a mother as she said, "they may never be able to fly like I wanted them to, but as long as they're happy and able to fly that's my job." The mother in the ballad eventually drowns. This study is presented with the hope that nurses will endeavor to help parents keep above water as they struggle to find help for their children.

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APPENDICES

APPENDIX A
THE UNIVERSITY OF TENNESSEE

351 Nursing Building
1200 Volunteer Boulevard
University of Tennessee in Knoxville
Knoxville, TN 37996-4180

INFORMED CONSENT FORM

INFORMATION

You are invited by Mrs. Josephine Wade, RN, MSN to participate in a research study. The purpose of the study is to describe the experience of being a parent or caregiver of a school age child who has been diagnosed with a mood related illness such as depression or bipolar disorder. This study may help nurses and other professionals more fully understand your experience in order to design approaches of care for families in the community and hospitals. The results of the study may be presented to the public at conferences and in journals and books. Mrs. Wade is a nurse who is conducting this study in order to complete her PhD in Nursing at the University of Tennessee in Knoxville. She is working with Dr. Sandra Thomas and a team of other university professors, who have an interest and experience in topics concerning parents and children with psychiatric illnesses.

INFORMATION

You will be interviewed by Mrs. Wade at a private location of your choice. The one time interview, which will take 1-2 hours will be audio taped because all of your words are important. If you agree, you may later be contacted by Mrs. Wade to discuss your opinion on the study findings. There will be from 6-12 people interviewed for this study which is due for completion in May, 2004.

BENEFITS & RISKS

The benefits to you are that you will have the opportunity to discuss your experience with an interested nurse researcher. Some people who have been part of studies like this one have found it helpful and a relief to talk about their experiences. There are minimal risks to you but a potential risk is that talking about some of your experiences may be emotionally upsetting. Mrs. Wade will be sensitive to your discomfort and you can end the interview at any time. Mrs. Wade is not a counselor but will provide you with information about how to access counseling in your area. You will be responsible for fees for services provided by these professionals.

CONFIDENTIALITY

All the study records will be kept confidential. No reference will be made in written or oral reports which could link you or your family members to the study. The typed transcripts may be discussed in a research group. The transcriptionist and members of this research group will sign a pledge of confidentiality. Data will be stored securely and will be made available only to persons conducting the study. The researcher, Mrs. Wade, will be the only person who will know

your name, address, and demographic information. This information, the consent forms, the transcripts, and the tapes will be kept in a locked file cabinet in Mrs. Wade's office, and the tapes will be destroyed after transcription. You may have a copy of the results of the study if you wish.

CONTACT INFORMATION

If you have questions at any time about the study or the procedures (or if you experience adverse effects as a result of participating in the study) you may contact the researcher Mrs. Josephine Wade, RN, MSN, c/o Dr. Sandra Thomas, 351 Nursing Building 1200 Volunteer Boulevard, University of Tennessee in Knoxville, Knoxville, Tennessee, 37996, telephone number (865)-974-7581. If you have any questions about your rights as a participant, contact the research Compliance Services Section at the Office of Research at (865) 974-3466.

PARTICIPATION

You do not have to participate in this research unless you wish to do so, and you may stop being part of the study at any time. If you decide to withdraw from the study before it is complete your data will be returned to you or destroyed.

I have read the above information and agree to participate in this study. I have received a copy of this form.

Participant's Name (print) _____

Participant's Signature _____

Date_____

Researcher's Name (print) Josephine Wade, RN, MSN

Researcher's Signature _____

Date_____

APPENDIX B

Phenomenology Group Member Pledge of Confidentiality

As a member of this phenomenology group I understand that I will be reading transcripts of confidential interviews. The information in these transcripts has been revealed by research participants who participated in this project in good faith that their interviews would remain strictly confidential. I understand that I have a responsibility to honor this confidentiality agreement. I hereby agree not to share any information in these transcriptions with anyone except the primary researcher of this project, her doctoral chair, or other members of this phenomenology group. Any violation of this agreement would constitute a serious breach of ethical standards, and I pledge not to do so.

_____ _____

Print Name Date

_____

APPENDIX C

Transcriber Pledge of Confidentiality

As the transcribing typist of this research project I understand that I will be hearing tapes of confidential interviews. The information in these transcripts has been revealed by research participants who participated in this project in good faith that their interviews would remain strictly confidential. I understand that I have a responsibility to honor this confidentiality agreement. I hereby agree not to share any information in these tapes with anyone except the primary researcher of this project. Any violation of this agreement would constitute a serious breach of ethical standards, and I pledge not to do so.

_____

Print Name

_____ _____

Signature Date

VITA

Josephine Wade has extensive clinical experience as a community health nurse in the USA and the United Kingdom, specializing in family, pediatrics, and obstetric nursing. She graduated from Northampton General School of Nursing as a State Registered Nurses and completed Health Visitor's certification at Chiswick Polytechnic, London, England. She received a BSN and MSN in Nursing Administration at the University of Alabama in Huntsville. She currently teaches nursing at the University of Alabama in Huntsville. She received a Doctor of Philosophy in Nursing degree from the University of Tennessee, Knoxville, in May, 2004.