CARING IN FAMILIES OF CHILDREN WITH AUTISM

by

Martha J. Haylor, R.N., M.N., M.S.

Dissertation Research

Presented to
Oregon Health Sciences University
School of Nursing
in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy

June, 1992

Approved:

[redacted]

Sheila M. Kodadek, R.N., Ph.D., Advisor

[redacted]

Christine A. Tanner, R.N., Ph.D., F.A.A.N., Reader

[redacted]

Mary Catherine King, R.N., Psy.D., Reader

[redacted]

Carol A. Lindeman, R.N., Ph.D., F.A.A.N.
Dean, School of Nursing

This research was supported, in part, by the Professional Nurse Traineeship Program, Grant Nos. 2 A11 NU00250-11 (1986-87), 2 A11 NU00250-12 (1987-88), 2 A11 NU00250-13 (1988-89), and 2 A11 NU00250-14 (1989-90), by the Institutional NRSA, Research of Families in Health, Illness & Transition, Grant Nos. 5 T32 NR07061-01 (1990-91) and 5 T32 N407061-02, and by Beta Psi Chapter, Sigma Theta Tau.

Acknowledgements

There are a number of people who made invaluable contributions to this research project. First, the families who shared their lives and their stories with me were asked to trust a member of the health care community with information that was deeply personal and sensitive. I hope I have done justice to the essence of their care, which comes from a variety of individual and family experiences. You have changed my life in significant ways as well as helped others understand what it means to love and live with a child affected by autism.

Second, a dissertation is a formidable task which in this instance was undertaken with the expert guidance of the women who served on my dissertation committee. Sheila Kodadek, through her knowledge of family nursing and personal experience with families of children affected by autism, planted the seed that inspired this research. Her guidance helped me through the conceptual, methodological, and creative swamps that accompany any large project. Chris Tanner created for me the possibility of doing interpretive research and throughout this project has participated in the ongoing search and challenge for clarity and understanding. Mary Kay King helped me sort out my own personal background meanings related to families, providing a safe and therefore stimulating environment for thinking it all through. Kit Chesla was not an official member of the committee; however, her work with families of persons affected by schizophrenia provided the blueprint for this study, and her ready willingness to share insights and experiences were priceless contributions. Although each of these women contributed to this project in their own unique ways, perhaps their greatest gift was the conveyed message that I was as important as the project.

Third, the analysis of the data would not have been possible nor as rich without the help of thoughtful and sensitive colleagues. In addition to the analysis assistance provided by members of my committee, I am also extremely appreciative for the time and energy given to this project by Terri Harvath, Debra Anderson, Linda Budan, Yoko Nakayama, Dawn Doutrich, and participants in the qualitative analysis study group and the family research issues group.

Finally, there are those people who contributed to this project through their everyday lived experiences with the researcher. Terri Harvath has been my friend and ongoing source of support through our years as doctoral students. Sally and Jamie, my family of today and central concern of my life, shared their love, patience, and support. Bob and Alice, my family of origin, laid the ground work for my understanding of the importance and power of caring for growth and healing.

Table of Contents

List of Tables

List of Figures

Caring in Families of Children with Autism

CHAPTER I

Mainstream American culture provides little opportunity for families to learn to parent or live with a child affected by autism. Prior to the 1970's it was common for children with developmental disabilities to be placed in private or public institutions, thereby removing the opportunity for the family or community to be involved in the everyday lives or care of these children. Since the 1970's, moving children with chronic and handicapping conditions from institutions has become the predominant political, economic, and humanitarian philosophy and reality. Subsequently, the primary care of children with autism has been assumed by the family, and, to a lesser extent, the community, resulting in increased personal, social, and economic demands placed on the family. That families of children affected by autism have coped with the caregiving demands of their children goes without saying, although the ongoing nature of their efforts and care and the intensity of commitment they bring to the process still may remain invisible to the general public.

The caring efforts of families with an autistic child must not be invisible to nurses, however. Clinical literature and parental reports (Ackerly, 1984; Marcus, 1977) have suggested that families feel resentful and dissatisfied with some of their encounters with professionals and have emphasized the need for professional understanding of how families manage their lives on a day-to-day basis. Health care and other professionals central to the care of families of children with autism have been criticized for being inadequately or inappropriately informed regarding the special needs of autistic individuals and their families (Konstantareas, 1989). Ackerly (1984) suggested that professionals share accurate information with families and approach them in a manner that is sensitive to the demands and rewards unique to families of autistic children as well as those inherent in all families. In other words, families want to be recognized for the uniqueness of their situation and also for the commonalities they share with all families. If nurses are to provide care to these families in a manner that promotes healthy functioning and minimizes stress of the individual family members and the family as a whole, then we must be knowledgeable of the different expressions that caring may take within families.

Knafl (1985) and Knafl and Deatrick (1987) point out that to date the research of family life of those with chronically ill or disabled children predominantly has taken one of two approaches. Investigators either have assumed that the disabled child is a source of chronic stress to which the family responds in a reactive sense, or researchers have made no assumptions about the inherent nature of a disability or the meaning of the disability to the family. Researchers who have assumed the disabled child is a source of chronic stress have focused on the outcomes of the disability on individuals in the family, using various objective measures of psychological and physical health. Those who have made no assumptions about the inherent nature of the disability have explored the meaning of the disability to the family and how the individual or family meaning shapes the family management of the illness or disability.

The central concern guiding this research was to bring the day-to-day family life of families of autistic children to the awareness of those who care for them. It was not the purpose of this research to explicate to what extent families care for their autistic child or other members of the family, but rather to describe in what ways they care. The conceptual view of the autistic child as a source of chronic stress and the impact of that chronic stress on the family has predominated in what little research has been done regarding families of autistic children in the last decade. Therefore, it was also the purpose of this study to extend understanding of living with and caring for an autistic child by exploring the meaning of having an autistic child in the family and how the meaning shapes the caring experience and family life.

Background

The prevalence of autism in the general population of children under 15 years of age is 4 to 5 per 10,000 (Coleman & Gillberg, 1985). Of those affected by autism 67 to 81 percent are mentally retarded with IQ's in the moderate range of 35 to 49; 25 to 33 percent develop seizures, most often during puberty; and 60 to 75 percent remain completely dependent throughout life (DeMyer, 1982). Estimates of the ratio of boys to girls affected by autism range from 3 to 1 (Wing, 1986) to 4 to 1 (Schreibman, 1988). For many years it was believed that autism was more prevalent in high social class families. However, a number of epidemiological studies have failed to find support for this belief and most experts in the field now believe that autism occurs in all social classes with normal distribution across classes (Coleman & Gillberg, 1985).

Experts have not always agreed on the diagnostic features of autism. The three primary criteria listed in the Diagnostic and Statistical Manual of Mental Disorders-Revised (American Psychiatric Association, 1987) contain the behaviors most commonly cited by others (Coleman & Gillberg, 1985; Schreibman, 1988). Perhaps the most intriguing and outstanding diagnostic feature of autism is the child's impairment in relating with people. Even within the family, autistic children may lack social responsiveness, affection, and appropriate play. In addition, autistic children experience delayed and abnormal development in their communication and imaginative activity. Language development in autistic children is highly correlated with IQ, just as it is in normal children. Some autistic children do not develop language and those who do may have speech characterized by echolalia and pronomial reversal. The third criterion for diagnosis is related to the child's restricted repertoire of activities and interests. Autistic children may engage in self-stimulatory activity such as head-banging, or be extremely upset with minor changes in the environment or daily routine. Any or all of these behaviors create care demands that may be baffling and unrewarding in nature to family members.

Theoretical and research tradition

Knowledge of the family experience of caring for an autistic child is limited because the quest for the ultimate cause of autism has preempted the concerns of parents as a focus for research. Initially, Kanner (1949) described parents of autistic children as mechanistic, undemonstrative, perfectionistic, and lacking in warmth. Psychodynamic theory was prevalent during this same time period and a clinical and research atmosphere of condemnation rather than concern for parents was created. The judgmental and pejorative portrayal of parents that followed is a reminder of the outcome of knowledge developed without appropriate attention to the integration of theory, practice, and research.

Investigators have ceased the etiological scrutiny of parents, and as a result an increasing number of investigations exploring the impact of the autistic child on the family have appeared in the last 20 years. The predominant conceptual approach to the study of families with an autistic child has been one that assumes the autistic child is a source of chronic stress even though parent accounts (Ackerly, 1984; Dewey, 1983) raise questions as to the appropriateness of this assumption.

The Double ABCX model, used in one of the larger studies of stress and coping in families of autistic children (Bristol, 1987; Bristol, 1984; Bristol & Schopler, 1983) exemplifies this approach. The model defines family adaptation as an outcome based on the success of family efforts to achieve new balance following a crisis (McCubbin & Patterson, 1983). Walker (1985) has been critical of the model and its underlying assumptions. First, she has criticized the use of an 'event' as representative of a stressor, the underlying assumption being that stress can be pinpointed to one particular experience. Walker assumes that stress and coping are processes and the use of an event as a benchmark of stress obscures the processes. Second, the model assumes a stress-free period prior to a crisis followed by coping strategies which return the family to the homeostatic pre-crisis state. "Life is stressful" and stress and coping are ongoing phenomenon so the assumption of a family life free of stress is questionable. Walker's third and strongest criticism of the model is the absence of a particular sociohistorical context within which the family experience may be understood. She emphasizes the need for the "contextual study of families under stress" using appropriate research methodologies to generate descriptive data from a variety of families undergoing different stressors within different contexts (p. 834).

Although the specific focus of this research was not stress and coping, in the process of describing caring in the study families instances of stressful situations and individual and family strategies used to manage the stress were elicited. The study addressed all three of Walker's concerns. First, the study assumed that the family identifies for itself that which is stressful, rather than the researcher assuming s/he knows a priori what is stressful for the family. Second, it was assumed that stress and coping are ongoing aspects of everyday life in all families. And thirdly, the present study extends the body of knowledge regarding family stress and coping by preserving the historical and contextual aspect of caring.

Conceptual Framework

One of the assumptions of this study was that an interpretive descriptive account of family caring would be derived from the lived experiences of families and that families would determine what was important to them. Based on this assumption it was necessary to have a conceptual framework that would be focused enough to address the phenomenon of interest, caring, and open enough so that individual and family meanings would be captured. In this study, the purpose of the conceptual framework was to provide a structure for describing and conveying the meanings of family care and the historical, cultural, and contextual context in which they reside. The term conceptual framework was used differently here than the more common understanding and usage of the term as an expression of a decontextualized approach to a phenomenon of interest.

Phenomenological view of caring

The phenomenological view of caring as described by Benner and Wrubel (1989) provided the conceptual background for this study. Caring, or having things matter, is what allows humans to be involved with those people, projects, or things that are important to them (Benner & Wrubel, 1989). Having something matter subsequently influences that which is perceived as stressful, the possibilities for coping, and that which is personally rewarding. Caring creates the situation where someone or something outside the self is of importance. Without caring all people and things would hold equal importance, hold equal potential for stress, options for coping, and sources of satisfaction and reward. The word 'caring' is used to capture what the authors consider the essence of why humans involve themselves in their world; caring is a combination of "thought, feeling, and action--knowing and being."

In this view, caring is situationally bound and influenced by the individual's concerns, background meanings, practices, and skill (Benner & Wrubel, 1989). The word "concern" describes the way in which humans are involved in their world. The question from a phenomenological perspective is not "to what extent" is one involved in the world, but rather "in what way" (which could include the extent of involvement) is one involved (Benner & Wrubel, 1989, p. 48). Specifically, families of autistic children have many areas of concern including their own needs for growth, needs of the autistic child for care, and social and recreational needs of the family. Each of these concerns creates possibilities for expressions of caring. Background meanings are implicit ways of knowing about the world in which one lives and come from the cultural, sub-cultural, family and personal life experiences. Background meanings are not in themselves things, like formal knowledge, but rather culturally given shared understandings that are used to filter human experiences. Practices are organized specific actions or non-actions related to caring for and about others; skill refers to the proficiency with which individuals provide care.

From this perspective contextual and situational aspects are also central to understanding caring and caring practices. For example, a family member may involve her or himself with the autistic child in a particular way that is shaped by background meanings, concerns and practices. However, different situations such as public versus private interactions may produce different demands that also influence the interaction. If a parent usually responds to a child's tantrums by using time-out, the demands of being in a public place where possibilities for time-out may be limited may produce different caring practices than those produced in the home.

The relevance of this phenomenological approach for studying individuals as well as families has been demonstrated (Benner, 1984; Chesla, 1988; Wrubel, 1985). Chesla (1988) explored the caring practices and coping of families of adult children with schizophrenia. Data were collected using individual and family interviews and extensive in-home observation. Four forms of interpersonal concerns were identified which shaped the caregiving experience in these families and brought into serious question existing theoretical formulations regarding the influence of the family on the health of the schizophrenic member.

Family theorists such as Sprey (1988) have also begun to acknowledge the role hermeneutic inquiry can play in furthering our understanding of family. Hermeneutic inquiry has been described as a challenging approach to addressing family processes that elude measurement through quantitative measures (Sprey, 1988).

> It is becoming rather clear that many questions about the intrinsic nature of marital and familial process cannot be exhaustively answered through the use of even the most sophisticated quantitative research techniques. Since hermeneutic thought takes this for granted, I assume that its influence on family theorizing will continue to grow.

Explanatory accounts of autism

Caring for individuals and families as they experience illness is a central focus of nursing. This study explored individual and family caring within the context of living with a child with special demands created by autism. Because autism is a developmental disability with medical, educational, and social understandings it was important to consider the social embeddedness of illness as a particularly salient background meaning. Kleinman (1988) and Kleinman, Eisenberg and Good (1978) have stated that illness is culturally shaped and their approach to understanding the illness experience is consistent with a phenomenological study of caring. How one perceives, labels, and copes with illness is embedded within a life history of family, social, and cultural experiences. More specifically, how one copes with an illness is related to the explanatory account one holds regarding the cause and necessary intervention of the condition.

A number of possible explanations and meanings shape the family experience of living with an autistic child. Research of perinatal, prenatal, genetic, biochemical, immunologic, and neurological factors as etiological components of autism provide a number of possible explanations for autism. Theoretically, psychogenic theories of autism are no longer in good standing; however clinically they may still influence family understanding of autism and clinical practice. Families also develop understanding about autism from their own experiences and the experiences of others. This practical understanding and knowledge comes out of their ongoing involvement with their autistic child and the social and cultural world in which they live.

In summary, the phenomenological view of caring provided the overall conceptual framework for the study. Within this view caring, or having people and things matter, is shaped by the background meanings, concerns, practices, and skill of the individuals within the family and the family as a whole. Caring is also shaped by the demands created by the interactive nature of the situation. The explanatory accounts of autism used by individuals and the family is a particularly important or salient background meaning to elicit. Understanding of the explanations of autism within the family aided further understanding of the possible expressions of caring in families of autistic children.

Problem Statement

Families of children affected by autism have always been important to the formulation of theoretical, empirical, and clinical understanding of autism. Presently, the clinical and research assumptions about families of autistic children emphasize the importance of the family as a reservoir of care rather than as a source of harm. Although much has been written about the families of autistic children, no systematic research had been undertaken from the lived experience of the family. There were no studies providing an in-depth description of the family life of those caring for a child with autism nor were there accounts of how families involved themselves in the everyday care of their autistic child.

Theories recommended for the study of families of autistic children, such as those that assume the child is a source of chronic stress, cover over the situational and interpersonal concerns related to caring by assuming an objective decontextualized stance. The phenomenological conceptualization of caring guiding this research has extended the knowledge provided by quantitative deductive studies. By understanding the contextual and situational aspects of caring in families of autistic children, the nurse can more meaningfully interpret the significance that things have for individuals and the family as a whole.

Research Questions

The overall aim of this study was to generate a descriptive interpretive account of caring in families of autistic children as evidenced in their lived, everyday experiences. The purpose of the research was to explore, from the perspective of the parents and siblings, what it is like to live with and care for children with autism. The family members' understanding of autism and the meaning of the experience, the concerns and care demands of family members living with autistic children, and in what way these background meanings, concerns, and demands shape caring within the family were investigated. The research questions were:

1. What are the family members' understandings of the cause of autism? What does the presence of an autistic child in the family mean to the individual family members? Is there a "family" meaning?

2. What are the care demands and concerns of families of children with autism? What are the caring practices solicited by these concerns and demands?

3. How do the explanatory accounts, the individual and family meanings of autism, and the personal background meanings of individuals influence caring for the children with autism and the family? Are there patterns of caring

that capture the family experience of living with a child affected by autism?

Significance

The results of this study have significance for nursing theory, practice, and research. The present study has generated an interpretive account of family caring. Interpretive theory is an description of a phenomenon presented in meaning terms (Benner & Wrubel, 1989). In contrast to formal theory, interpretive theory does not assume an objective, decontextualized stance of explaining and predicting outcomes of family caring. Rather, the focus is on how the pattern of caring in one family is similar and dissimilar to the content and meanings of caring that may exist in other families of children with autism. Interpretive theory is derived from the study of everyday practices and is contextually and culturally embedded.

The findings of this study will contribute to the clinician's understanding of the individual and family experience of caring for an autistic child. The study has the potential to add depth and richness to the present theoretical understanding of these families by attending to the contextual and cultural as well as the rewarding aspects of caring. Thomas (1987) has recommended that nurses working with families of children with developmental disabilities join with the family as partners in care. By understanding the explanatory accounts, individual and family meanings, demands, and concerns that shape family caring, practicing nurses will be better able to interpret that which is significant or of value to the family thereby enhancing the development of a caring partnership. In addition to the potential contribution to nursing practice, the knowledge generated in this study may also prove useful to other families of autistic children.

Finally, the descriptive nature of this study will provide a basis for further research regarding families of children affected by autism and for the investigation of appropriate nursing interventions with these families. Families whose everyday lives are shaped by unique understandings of autism, concerns, background meanings, and demands require tailored approaches to nursing care. Until we understand families from this perspective, we are left to conduct further research from a position that assumes that it is not important to understand what is significant to families, or from a position that assumes that we know what is significant to families. We run the risk of perpetuating research that leads to a flat approach to nursing intervention, a position that assumes that all interventions will hold equal value to all families in all situations. The next two chapters of the dissertation will present the literature relevant to the study of families and autism and the study methodology respectively. Chapters IV, V, and VI will describe the study findings related to the explanatory accounts of autism; care demands and concerns of living with a child with autism, individual meanings of autism and the individual caring practices drawn forth; and family meanings and family caring patterns. Finally, Chapter VII will address the theoretical, clinical, and research implications of the study.

CHAPTER II

Review of Literature

The phenomenological perspective used in this study emphasized the importance of history and temporality in understanding a phenomenon. Within this perspective the present does not exist separate from the past or the future (Benner & Wrubel, 1989). In order to appreciate the influence of history as it shapes understanding of the family and autism today, a brief overview of the psychogenic theories that guided early research and practice is presented. Examples of the portrayal of parents by these theories and theorists is also provided. The remainder of the literature review includes research regarding the impact of autism on the family, the caring practices of parents of autistic child, coping in families of autistic children, and family styles of caring for a child with autism.

Early psychogenic theories of autism

Historically, the search for the cause of autism was guided by one of three theories: (1) the "nurture" theory which stated that autism was caused by a normal healthy infant's exposure to extreme early stress or cold, non-responsive parents; (2) the "nature-nurture" theory in which autism was thought to be the result of a somewhat vulnerable infant's exposure to non-responsive parents; or (3) the "nature" theory whose proponents believed that autism was caused by an organically vulnerable infant whose response to the world was inherently different than infants not affected by autism. Kanner (1943) originally stated his belief that children with autism suffered from an inborn inability to respond to the world. In spite of this belief, the nurture and the nature-nurture theories were initially very popular and from the mid-1940's through the early-1970's parents of children with autism were scrutinized in research and clinical practice as etiological agents of the disorder.

The nurture or nature-nurture explanatory models of autism evolved during the time period that psychodynamic theories were prevalent in the medical culture, and the psychogenic theories of autism were initially supported by a number of clinical articles (Eisenberg, 1956; Eisenberg & Kanner, 1956; Kanner, 1949). Cold, mechanistic, and detached were the adjectives used in initial clinical articles to describe the caring practices of parents. Early research studies provided further support for the nurture and nature-nurture theories (Behrens & Goldfarb, 1958; Block, 1960; Ogdon, Bass, Thomas, & Lordi, 1968) although much of the early research with families of children with autism has been criticized as conceptually and methodologically unsound (Schreibman, 1988; Wing, 1976). A cornerstone of the critique was based on the occurrence of conceptual and clinical confusion in differentiating between childhood autism and childhood schizophrenia that existed at that time. The confusion resulted in research that included parents of children affected by both conditions being placed in the same experimental group. Methodologically, reliability and validity of the self-report and projective techniques used in these studies have been questioned. The original description of autism by Kanner (1943) was based on careful documentation based on intense clinical observation. However, the abnormal characteristics attributed to parents were never systematically or empirically observed but rather were based solely on anecdotal evidence. Finally, the impact of a deviant child on the parents was overlooked as a possible explanation when interpreting the direction of causality. Cantwell and Baker (1984) reported that the majority of studies supporting parental pathology as an etiological agent of autism were conducted prior to 1970; those studies finding little or no support for this explanatory model occurred after 1970.

The work of Bettelheim (1956;1967) exemplified the conceptual and clinical tone of those adhering to the nurture and nature-nurture theories. Bettelheim believed that autism was caused by parents directing extremely negative feelings to a specific child. As a result the child found the world an undesirable place and purposefully withdrew into him/herself. Bettelheim's thoughts regarding the etiology of autism were greatly influenced by his observations of the human response to the concentration camps during World War II. He observed that given exposure to extreme uncontrollable danger, humans resigned themselves to an inner world. Interventions for autism based on this theory involved removing the child with autism from the family, although the mother was viewed as the main problem as exemplified in the following quotes from Bettelheim's work (1956):

> Basically, what such a child needs is a mother free of the emotional demands so many mothers make, so that he can benefit from mothering without having to respond to it (p. 516)...We must protect such a child against any hostility coming from the external world, most of all, from his parents... (p. 517).

Although the mother-child relationship was most often the primary focus in the early phases of knowledge development regarding autism, the role of the father was also scrutinized. Eisenberg (1957) stated that the father's influence could be direct, through his interactions with his child, and indirect, given that any inadequacy in the performance of his role would impact the adequacy of the mother's role. Based on a review of 100 case histories, Eisenberg (1957) identified the following personality characteristic evident in 85 of 100 fathers: obsessive, detached and humorless, perfectionistic, and intelligent but unoriginal in their thinking. A number of the clinicians, researchers, and theorists who explored the influence of parent characteristics on the development of autism advised caution in oversimplifying a causal relationship between these phenomena (Eisenberg, 1957; Eisenberg & Kanner, 1957; Kanner, 1943; Ogdon, Bass, Thomas, & Lordi, 1968). However, the notion that parents of autistic children somehow contributed to the etiology of autism persisted for a number of years.

The investigation of parents and families as etiological agents in their child's autism has declined markedly for two reasons. First, as research designs became more sophisticated and conceptually clearer empirical evidence failed to support the nurture and nature-nurture theories (Cantwell, Baker, & Rutter, 1978; MeDyer, Hingten, & Jackson, 1981). Second, at the same time that psychogenic theories were failing to find support, research in the fields of genetics, biochemistry, immunology, and neurology was producing evidence supportive of the existence of significant organic etiological components in autism. At present, although the specific etiology remains unknown, research has demonstrated that a number of biological mechanisms, including genetic, prenatal and/or perinatal infection, organic brain dysfunction, and metabolic conditions act singly or in combination to produce the autism syndrome (Coleman & Gillberg, 1985; Rutter & Schopler, 1978).

Although parents and families have no longer been subjected to blame for their child's autism by experts in the field, myths from this earlier time still exist in the present among some nurses and other health care professionals. A survey conducted with 183 nurses prior to their attendance at an educational program about autism revealed that 38 percent of the participants believed that cold, non-relating parents could cause autism, 25 percent believed that autism was caused by a psychological disturbance, and 23 percent believed that autistic children should not be educated in the public schools (Gilliam, Unruh, & Haley, 1980). In order to better understand the experiences of parenting an autistic child, Dudziak (1982), a psychiatric mental health nurse, interviewed the mothers of five autistic children. Several mothers reported incidents of rejection, refusal to treat their child, and misinformation involving health care professionals. While seeking evaluation for her child as a pediatric hospital, one mother was given a copy of a 1943 article that stated autism was caused by cold, unfeeling parents.

Several conclusions based on the legacy of this period were important in considering further research with families of children with autism. The majority of studies had been undertaken to prove or disprove a parental role in the etiology of the condition. Presently, most scholars and clinicians in the field of autism do not believe that autism is caused by parents. Theoretically, the nurture and nature-nurture theories are outdated but they produced ideas that may be a clinical reality among some nurses and other health care professionals today. This early history of autism also points out the ethical and professional danger of unexamined theoretical assumptions and unsound research methodology as they impact the lives of those we care for in our nursing practice.

The stress of living with a child affected by autism

Cantwell and Baker (1984) have recommended that the most productive approach to research with families of children with autism is to conceptualize the situation as one of chronic stress. This recommendation is consistent with that of other theorists investigating the family experience of having a chronically ill child (McCubbin & Patterson, 1983). Although the theoretical underpinnings of recent research on families of autistic children have not always been made explicit, the underlying assumption has been that the autistic child is a source of chronic stress to which the family adapts with varying degrees of health. Based on this premise, researchers have explored the family consequences of living with a child affected by autism from a number of perspectives including: impact on the family as a whole, stress associated with the growth and development of the child, stress of parenting an autistic child compared with that of parenting children with other disabilities, and the impact of the child with autism on individual family members.

Impact on the family. DeMyer and Goldberg (1983) investigated the nature of the impact of the child with autism on the family. All but 3 of the 23 families included in the research had been followed clinically by the authors since the child's preschool years. Children ranged in age from 9 to 29 years and data were collected from 19 mothers and 2 fathers. Results were based on interviewer and clinician ratings of the impact of autism on 11 aspects of family life. The 11 aspects of family life most affected during all developmental phases of the child were presented in the rank order of mean group severity ratings and included: family recreation, finances, mental and physical health of parents, housekeeping, meeting the needs of siblings, maintaining social relationships, disrupted sibling relationships, strained marital relationship, inhibited personal development of each family member, and relations with relatives. The investigators found that the intensity or severity of the child's impact on the family was related to future need for institutionalization of the child. Approximately 67 percent of the adolescents over 14 years of age and those with symptoms judged severe were eventually placed in institutions by their families.

Developmental aspects of stress. Bristol and Schopler (1984), Dudziak (1982), and Zoltak (1986) have addressed the developmental nature of the caregiving demands in mothers of children with autism. Based on their experiences in an ongoing program of research, Bristol and Schopler (1984) identified stressors common during the preschool, school-age, and adolescent periods. During the preschool years, the lack of a definitive diagnosis greatly increased the stress related to the ambiguity of the child's condition. Once the diagnosis had been made, learning to live with the diagnosis could begin, a process that spanned the lifetime of the parent and child. Chronic fatigue, constant vigilance, and feelings of inadequacy regarding appropriate parenting were also sources of stress reported during the preschool years (Bristol and Schopler, 1984; Dudziak, 1982; Zoltak, 1986). Parenting concerns of the school-age child with autism shifted to finding adequate educational services, managing inappropriate public behavior, and trying to maintain family stability. Increased physical size, sexual maturity, and increasing public intolerance for inappropriate behavior were concerns of parents of adolescent children (Bristol and Schopler, 1984).

Parenting stress of autism contrasted with other disabilities. Research comparing the stress experienced by parents of children affected by autism with that of stress experienced by parents of non-handicapped children or children with other disabilities have produced inconsistent results. Wolf, Noh, Fisman & Speechley (1989) examined the relationship between parenting stress, social support, and the level of depressive symptoms reported by parents of autistic children, Down's Syndrome children, and children without developmental disabilities. The non-disabled children were divided into two groups matched for developmental age and gender. This research is notable in that 123 mothers and 115 fathers participated in the study, with a 100 percent response rate. The stress associated with parenting the child with autism, as measured by a parenting stress index, was significantly higher for mothers and fathers than that of parents in the other three groups. Mothers of autistic children reported significantly more depression than did mothers of non-disabled children, however, there were no significant differences between mothers of autistic children and mothers of Down's Syndrome children. Mothers in all four groups reported more dysphoria than did fathers and no significant differences were found between groups of fathers in the amount of depression experienced. The researchers also found that perceived social support buffered the effect of parenting stress on depression of mothers and diminished the vulnerability of fathers.

Holroyd and McArthur (1976) hypothesized children with autism would have a more stressful influence on their mothers and families than did children with Down's Syndrome or those from a child psychiatry outpatient clinic on their respective mothers and families. One hundred mothers representing the three groups completed the "Questionnaire on Resources and Stress" instrument, a problem-focused measure of the impact of caring for a handicapped child on the parent. Mothers of the children with autism reported significantly more problems than mothers of the other two groups. Specifically, they were more upset and disappointed about their child; expressed more concern about the long-term dependency, lack of community resources and impact of the child on the family; and were more aware of behavior and personality problems of their child. Mothers of the children with autism and mothers of children with Down's Syndrome also shared some problems, including poor health, limited opportunities for themselves and other family members, excessive time and care demands, and pessimism (or perhaps realism) about the child's future.

In contrast, Koegel, Schreibman, O'Neill, and Burke (1983) found no evidence to suggest that families of children with autism experience a greater overall stress reaction to having a disabled child. Based on standardized instruments designed to measure the personality characteristics of the parents, marital quality, and atmosphere of the general family system, no statistical differences were found between parents of autistic children and normative groups. The investigators concluded that a general overall stress reaction may not exist in these families and that a more plausible perspective is to view parental stress as situational.

From a clinical standpoint, Marcus (1977; 1984) has identified burnout as a central concern for intervention with families of persons with autism. His description of the stresses associated with the family experience was informed by his extensive clinical practice. Having an child with autism means constant worry, anxiety, physical and mental fatigue. Life decisions are impacted, such as remarriage for a single parent or a family move to another community. Family life is altered in that marital tension may arise and attention to the needs of other children may be diminished. Long-term caregiving without respite, obtaining proper diagnosis, locating appropriate services, loneliness and isolation, and inadequate support services are also sources of stress in families.

Impact individual family members. The majority of studies investigating the impact of the child with autism on the family have focused on the impact of the child on the mother and the mother's reports of the impact of the child on the family (Morgan, 1988). While this strategy is consistent with family research in general, including fathers and other family members in research would expand our knowledge of family. Recent research on stress and coping among families of autistic children is noteworthy for the inclusion and participation of fathers (Koegel, Schreibman, O'Neill & Burke, 1983; Milgram & Atzil, 1988; Wolf, Noh, Fisman & Speechley, 1989).

Bristol (1984) identified factors related to increased stress in mothers of children affected by autism. Data were gathered from mothers of 40 children ranging in age from 4 to 19 years. Unsuccessful coping in mothers was associated with characteristics of the child such as age and gender, with older rather than younger and male rather than female children producing more stress among their mothers. These characteristics of the child, when combined with a lack of community resources and limited opportunities for future independent living, accounted for approximately 75 percent of the variance in reported maternal stress. Factors not associated with increased stress included: socio-economic status, maternal age, number of children in the family, average IQ of the autistic child and severity of autism.

Research on the impact of the child with autism on siblings and extended family members is very limited. McHale, Simeonsson, and Sloan (1984; 1986) compared the sibling relationships of children with autistic, mentally retarded, and non-handicapped brothers and sisters. Although the group means reflecting overall adjustment of the siblings were not significantly different, the children with handicapped siblings were much more variable in describing very negative and very positive relationships. Age, gender and family size were not as highly correlated with the quality of the sibling relationships with handicapped children as were specific problem areas such as perceptions of parental favoritism and the non-autistic child's coping ability.

Only one study was identified that examined intergenerational relationships between parents and grandparents of children with autism (Harris, Handleman, & Palmer, 1985). Mothers, fathers, grandmothers, and grandfathers completed a questionnaire describing their view of the autistic child, their view of the impact of the child on themselves and the family, and relationships between the parents and grandparents. When the generations differed in their views, grandparents consistently took the more positive, optimistic or less burdened view of the impact of the child in the three areas studied.

In summary, research on the impact of the child with autism on the family consistently points out the situational and contextual aspects of stress. Each developmental phase of the child is associated with unique care demands and therefore provides different sources of stress for parents. Differences between stress levels reported by parents of disabled children with different diagnoses were associated with the care demands of the children, such as the difficulty of the child's personality and concerns about long-term dependency. Objective decontextualized measures, such as severity of autism, child's IQ, number of children in the family, and socioeconomic status were not predictive of increased stress in families. There is some evidence to suggest that mothers and fathers of autistic children report significantly more stress that parents of other children.

In contrast, other investigators have indicated that in spite of the increased stress experienced by family members, there were not significant differences in the personality structure, marital quality, and general family atmosphere in families of autistic children, further indicating the importance of understanding how parents cope with their situations.

Caring practices of parents

Studies designed to investigate parent characteristics as etiological contributions to autism also provided insight into parental responses to having a child with autism. Parents of autistic children were compared to parents of children without disabilities and to those of children with other types of disabilities (DeMyer, et al, 1972; Cantwell, Baker, & Rutter, 1979; Cox, Rutter, Newman, & Bartak, 1975).

Based on results of interviews and two standardized measures of obsessionality and neuroticism, Cox, et al. (1975) concluded there were no significant differences between parents of autistic children (n=19) and parents of dysphasic children (n=23). Obsessive and neurotic characteristics were identified initially by Kanner (1949) as being highly prevalent in parents of autistic children. Not only did the results of this study fail to provide support for the nurture or nature-nurture theories, they also indicated that even though parents of autistic children are advised to provide structure and routine for their child, parents did not become obsessive or neurotic in light of the care demands. Parents in both groups responded with warmth and emotional demonstrativeness toward their disabled children, although mothers of autistic children were somewhat less warm to their autistic child than they were to other children in the family. Both groups socialized with family and friends to a similar extent. Two-thirds of the mothers in both groups reported depression at one time or another.

Another report based on the same study (Cantwell, Baker & Rutter, 1979) indicated that fathers of autistic children spend twice as much time in pleasurable activities with their children than do fathers of dysphasic children. However, there were no differences overall between the two groups on a measure of the qualitative aspects of family relationships, parent-child interaction, and the style of child care.

DeMyer et al. (1972) and Allen et al. (1971) explored the relationship of the diagnosis of autism in a child and the caring practices, amount and quality of infant stimulation, parental warmth, and intellectuality of the parents. Using a matched sample, parents of autistic children (n=33) and parents of normal children (n=33) were compared with a group of parents of brain-damaged children who were not matched on the criteria. Interview data were coded using an objective rating item scale. No differences were found between the matched groups with regard to expressed parental warmth, caring practices, or infant stimulation. Parents of autistic and brain-damaged children were found to emphasize intellectual pursuits for their children less than did parents of normal children.

These studies were designed to test the nurture or nature-nurture theories and they provided evidence that was damaging to these theories. They also provided information about how parents responded to the experience of caring for an autistic child. The results indicated that parents responded with warmth and caring practices that were consistent with what parents of other disabled and normal children provided. Parents de-emphasized the importance of their child achieving in areas that were unlikely, given the capabilities of the child. These studies also indicated that parents attempted to provide the care that was needed and to meet other social and family responsibilities, often at the expense of their own mental health.

Family coping

Literature regarding family coping in families of children with autism is very limited. However, researchers have begun to address the need for understanding the family experience. Bristol (1987) investigated the relationship between a number of individual, contextual, and family variables as they contributed to the healthy adaptation of families enrolled in North Carolina's statewide program for children with autism and communication disorders. McCubbin and Patterson's Double ABCX or Family Adjustment and Adaptation Response Model (McCubbin & Patterson, 1983) provided the conceptual underpinnings for the study. Specifically, the severity of the child's handicap, the pile-up of other family stressors, family cohesion, the mother's attribution of blame for her child's condition, the definition of the handicap as a family crisis, and patterns of coping were examined for their ability to predict healthy family adaptation, operationalized as maternal depression, marital adjustment, and the quality of parenting. Data were gathered from 45 mothers of children with autism or other severe communication impairments prior to their evaluation at the program. A variety of data collection strategies were used including maternal self-report on standardized measures and an interviewer/observer rating of parenting quality based on in-home observation and interview.

The findings provided information related to the individual responses of the mothers, their relationships with their spouses, and their relationships with their disabled children. The Double ABCX model accounted for 33 percent of the variance in maternal depressive symptoms, 53 percent of the variance in marital adjustment and 55 percent of the variance in the quality of parenting. Specifically, the pile-up of other stresses made the most significant contribution to the prediction of maternal depression and marital adjustment and a significant contribution to the quality of parenting. Informal support was a significant contributor to parenting quality and marital adjustment. The severity of the handicap did not significantly contribute to any of the measures of the dependent variable. However, severity of handicap approached significance in relation to marital quality in that more severely handicapped children tended to have parents with better marital adjustment. Increased self-blame predicted poorer marital adjustment and quality of parenting. The findings related to the affects of family cohesion were mixed. Increased family cohesion was positively correlated with better family adaptation. When entered into the regression equation with informal support, increased family cohesion was negatively related to adaptation. In discussing this finding Bristol (1987) sites the complex nature of social support that, depending on the situation, may be a resource or a source of stress.

Active coping strategies were measured by the Coping Health Inventory for Parents and made a significant contribution to the prediction of the parenting quality but not to the prediction of marital adjustment or maternal depression. In earlier reports of the same research (Bristol, 1984; Bristol & Schopler, 1983) specific coping strategies found to be helpful by mothers were identified. Three of the ten most helpful coping strategies were family related: talking things over with a spouse, building a closer relationship with a spouse, and maintaining family stability. The remaining seven were focused on individual beliefs about the self and others and active involvement in helping the child with autism. Mothers who used a greater number or variety of coping strategies had a significantly higher observer rating regarding the quality of parenting.

Based on Cohen and Lazarus' (1979) view of stress and coping Bristol and Schopler (1983) have also identified specific instrumental and palliative coping strategies used by parents of children with autism. From their clinical and research experiences with families, the authors stated that instrumental coping strategies such as parental involvement as a co-therapist for a child has repeatedly been demonstrated to be beneficial to parents. Identified palliative strategies, those that help the individual feel better about a stressor, included taking antidepressants, eating, sleeping, or physical exercise. Milgram and Atzil (1988) investigated the relationship of objective measures of functioning in the child with autism, subjective reports of parenting burden and the association of each with the mental health and life satisfaction of the parents. The study was conducted with the mother and father (n = 46) of 23 children in Israel. The investigators found that mothers provided approximately two-thirds and fathers approximately one-third of the child care and that mothers and fathers believed that fathers should be more involved in active caregiving. Increased life satisfaction in the parent was associated with increased satisfaction with the parenting measures. No correlation was found between parental life satisfaction and the measure of adaptive behavior in the child. The authors concluded that life satisfaction has more to do with how one copes rather than the atypical development of a child.

Historically, families of children with autism were advised to place their affected child in an institution as a means of relieving parental and family burden of care. However, parents of children with autism who were institutionalized did not report lower levels of stress than parents of non-institutionalized children based on research by Holroyd, Brown, Wikler and Simmons (1975). Interviewer ratings of current family stress did not differ in distribution between the two groups. Parent scores on three scales of an instrument designed to assess the impact of family caregiving for a chronically disabled child revealed that children with more severe symptomatology were more likely to be institutionalized, findings consistent with those of other researchers (Bristol & Schopler, 1983). Mothers in families classified as high stress by an interviewer scored higher on five scales of this same measure than did mothers classified as low stress: lack of social support, lack of family integration, pessimism about the future, financial problems, and limits on the family's opportunities because of the child with autism. This study provided further support for investigating the situational aspects of stress and coping in these families rather than treating stress and coping as though they were objective qualities that one either has more or less of.

Although research on coping in families of children with autism is limited it has identified individual, family and contextual impediments and resources to healthy family adaptation. What the research does not provide is access to how the meaning of the experience, and what stands out as important to families shape the expressions of caring.

Paradigms of family caring

Creak and Ini (1960) were among the first to question the psychogenic origin of autism. During clinical observations and research interviews the authors were impressed by the "depth of feeling and compassion" expressed by parents of children with autism and the apparent normality of the majority of siblings in these families. In a descriptive study the researchers investigated social class, parental age, incidence of parental mental illness, parental personalities, parental attitudes toward their child, and marital state among mothers and fathers of 102 children with autism diagnosed by the authors. The authors concluded that no evidence was found to support the theory that parental personalities or child-rearing attitudes contributed as etiological agents in autism. In developing the rating scale used for analyzing interviews and clinical data the authors identified four types of parental involvement with the child: "over-identified", characterized by a close identification with the child and possible denial of the abnormality of his symptoms; "sympathetic", the 'normal' caring attitude a parent would have toward a child who needs special help; "puts up with", a more resigned and detached involvement than the sympathetic parent; and the "overtly hostile", characterized by desertion of the family or open rejection of the child with autism. This study was the first to describe a range of parental responses to rearing children with autism.

Clinicians have also noted their observations of different family responses based on their years of experience with these families. Harris (1982) identified four of the more common family patterns observed over a period of 8 years of teaching parents how to provide behavior training for their children with autism. Using Minuchin's family therapy theory as a conceptual guide the four family patterns included: "the poor sick child", "it's just the three of us", "this child has come between us", and "mother's little helper." In the "poor sick child" family the mother becomes over involved with the autistic child to the exclusion of the father and other children in the family. The diagnosis of autism absolves the affected child from responsibility for his/her behavior in this family and discipline and behavior training is very lax. In the "it's just the three of us" family, both parents may be over involved with the child to the exclusion of the other children in the family. The parental over involvement may take the form of investing tremendous time and energy into the behavioral treatment of the child with autism, or may take the form of an extreme lack of discipline. Siblings in these families may passively accept their lack of attention or may rebel. The "this child has come between us" family is characterized by parental conflict regarding the over involvement of one parent with the child affected by autism to the exclusion of the marital relationship. The marital relationship is also of secondary focus in the "mother's little helper" family. In this family an older sibling joins with the mother to provide the care for the autistic child to the exclusion of the father. Harris (1982) suggested that although there may be many different expressions of healthy family adaptation to a child with autism, ideally there should be some underlying commonalities including: parent agreement on management and goals for the child; shared parental involvement with the affected child and other children in the family; and attention to the individual and marital needs of the parents.

Summary

Methodologically sound research has produced consistent findings indicating that parents do not cause autism. Subsequently, attention was turned to identifying variables that correlated or predicted healthy family adaptation when there was a child with autism in the family. There have also been some beginning attempts to qualitatively conceptualize the parent-child involvement style in these same families. Qualitative descriptors of family patterns of involvement have been based on clinical observations using a family therapy framework. The contribution that reflection on clinical practice can offer is highly valued, however no "healthy" patterns of family adaptation were identified in the literature.

An assumption of many theoretical approaches to the study of families of children with autism has been that it is a stressful situation although there have been conflicting research findings regarding the amount of stress experienced in families. Characteristics of children with autism that parents find troublesome and difficult to respond to, such as personality characteristics and developmentally inappropriate behavior, have been identified. Reports have indicated that parents of autistic children are no more obsessive or neurotic, nor any less warm or responsive than are parents of children with and without disabilities. Research findings indicate that mothers may be more adversely affected than fathers and that autism is more demanding for families than other disabilities.

This is valuable information for nurses beginning to think about nursing care of families who have children with autism. If theory is a road map that helps one think about a particular phenomenon then the current literature suggests that clinicians should be concerned for mothers and sometimes siblings. It is unclear whether fathers are at risk. Families who are isolated, over-extended, and have disparate approaches to problem-solving are at higher risk for "unhealthy" adaptation. As children with autism grow and develop the family will be called upon to adapt their caring approaches to address the evolving child. Institutionalization is not necessarily the panacea that common sense advice might suggest. Our current understanding of families who have children with autism guides us in certain directions and points out major areas of concern along the way. What the current knowledge base does not yet inform us about is the qualitative nature of living in families who have children with autism. It does not inform us about the more particular aspects of the journey such as family caring efforts that enhance smooth functioning or those that might threaten breakdown of the family. A descriptive interpretive account of family life would facilitate the sensitization of nurses to the family experience and open up new possibilities for developing a caring partnership with these families.

Understanding the situational and cultural aspects of caring in families of children affected by autism would add depth and sensitivity to nursing's current understanding of life in these families. Methodologically, the most common approach to the study of the highly contextualized phenomena of care has been with objective decontextualized measures such as standardized self-report of objectified ratings of qualitative data. While there is increasing attention to the experiences of fathers, siblings, and extended family members, these family members are still under represented in family research in this area. An interpretive account of the situational concerns and demands of the family experience of caring will provide nurses different access to families of children with autism than has been provided by other research to date.

CHAPTER III

Methods

Hermeneutic methods were used to guide data collection and analysis in this study. The goals of hermeneutic inquiry are to understand everyday practices and experiences, to discover the common meanings in similar situations or among people who share a culture (Leonard, 1989), and "to find exemplars or paradigm cases that embody the meanings of everyday practices in such a way that they are not destroyed, distorted, decontextualized, trivialized, or sentimentalized" (Benner, 1985, p.5). The purpose of hermeneutic or interpretive methods is to uncover historical and contextual background meanings and to understand their influence on human behavior rather than to explain human behavior through "context-free" elements (Dreyfus, 1983). In this study, the purpose was to understand from the perspective of the individuals and the family as a whole, how the explanatory account of autism and other background meanings, and the demands and concerns of living with a child with autism shape the caring experience as evidenced through language and daily practices. Caring in families of children with autism was examined from a position intended to capture the rewarding as well as the demanding aspects of day-to-day living in addition to the other cultural, historical, and situational aspects.

Interpretive research is based on assumptions about human beings that differ from those of a positivist view of humans; therefore data collection and analysis strategies congruent with these assumptions were used. This section will begin with an overview of the Heideggerian view of humans from which the conceptual background of this study is drawn. The remainder of the chapter presents specific information regarding the sample, setting, ethical issues in family research, and data collection and analysis procedures. In conclusion, specific measures taken to address the scientific adequacy of the study are presented.

View of Human Beings

From a Heideggerian phenomenological view, humans live in the world directly (Benner, 1985; Benner & Wrubel, 1989; Dreyfus, 1983; Leonard, 1989). That is to say, because we are involved or situated within a culture we come to understand what is meaningful and how we are to behave within that culture (Dreyfus, 1983). The world exists a priori and is conveyed through history, practices, and language of those who share a particular culture. The shared practices and understandings, or background meanings, are taken up by the individual in a nonreflective way through language, cultural practices, and family traditions. In other words, no one teaches us in a formal way how close to stand to people in different situations, but we know that professional versus intimate encounters are accompanied by different measures of physical closeness. A Heideggerian view of human beings contends that the everyday world of common understandings and practices comes before theoretical understanding and is so pervasive in our lives that it only shows up during times of breakdown (Dreyfus, 1983).

In addition to being situated and involved in a world through which we obtain meaningful knowledge, we also are beings for whom things matter (Benner & Wrubel, 1989; Leonard, 1989). Our humanness means that all people or events do not hold equal value or importance and therefore we do not respond in standardized ways. Human concerns, or how we are involved in the world, are qualitatively different given the cultural, historical, and individual background of the person within the context of a particular situation. Because humans are constituted by and involved in their worlds, and because not all events, things, or people hold equal value, in order to understand human 'being' the researcher must be involved in the world of those of interest.

A third aspect of being human, from a Heideggerian view, concerns the role of the body in knowing. This phenomenological view of the body is one that assumes the body is in itself a way of knowing rather than an instrument for sensing the objective world (Benner & Wrubel, 1989; Dreyfus, 1983; Leonard, 1989). Feelings and meanings are not just thought about, they are experienced in the body. Embodied intelligence is what allows us to grasp the significance of a situation immediately, recognize familiar faces, and perform complex skilled activities. In families, embodied intelligence is at work when parents and children alike recognize certain facial expressions as those of pride, pleasure, guilt, or trouble.

Implications for research

An understanding of human experience and action requires obtaining knowledge about the structures and circumstances that create the experienced world, or meaning systems, from which actions and expressions are derived (Polkinghorne, 1988). This was accomplished by collecting examples of the expression of these meaning systems' through interviews and observations which were then analyzed systematically using hermeneutic techniques. In order to uncover the meaning systems, or background meanings, concerns and practical knowledge of families, the research accessed families in the process and context of being families. This meant studying them in their homes involved in their everyday world. Because language is a primary way in which a culture is communicated, individual and family interviews were conducted. Language alone may not be enough to capture the everyday, habitual knowledge of families as its invisibility makes it difficult to articulate fully. For this reason, in-home observations were also conducted.

Study participants

A sample of 10 families was recruited for study participation. They were solicited through the investigator's attendance at a support group for families of children with autism, a parent advocacy group, and by word of mouth. Family members of children 12 years of age or younger who had been diagnosed with autism for at least 6 months were invited to participate. The parents of the child provided the point of entry into the family and each parent plus any other adults significant in the everyday lives of their children were also invited to participate. In addition, siblings 6 years of age and older who wanted to participate were included. All but one family was the biological family of the child with autism, and the remaining family was a blended family.

Two families withdrew from participation after originally agreeing to participate. A third family who had agreed to participate was not contacted further after the researcher learned that their child with autism had died unexpectedly. The families of seven boys with autism constituted the final participants. The boys ranged in age from 4 to 11 years; parents ranged in age from 23 to 49 years (3 grandparents were also interviewed although their data are not included in the following analysis). Family incomes ranged from $10,000 to approximately $60,000 per year. The number of siblings (N=7) in each family ranged from 0 to 2, with a mode of 1. Of five siblings over the age of 6, 3 agreed to be interviewed. All siblings were included in observations when they were in the home during these times.

The parents of the children with autism were asked to rate the severity of their child's condition based on a scale of 1 to 10 with 1 being a minimally affected child and 10 being a severely affected child. Responses to this question ranged from 2 to 9. The ways in which the children with autism were affected are described in Table 1.

Setting

Individual interviews were conducted in a setting that accommodated the desires of the participants, and for the majority, interviews were conducted in a private atmosphere within the home although 2 parents preferred an office setting. Observations and family interviews were conducted in the home.

Table 1

Functional Characteristics of Children with Autism

Functional Area	Number
Communication	
Nonverbal and limited communication strategies	2
Nonverbal with repertoire of communication strategies	3
Verbal with few or no communication difficulties	2
Socialization	
Responsive, loving family relationships	7
Temper tantrums	2
Age-appropriate peer relationships	0
Repertoire of activities	
"Stimming" (self-stimulatory activities)	7
Self-injurious	1
Ritualistic behavior/inability to make qualitative distinctions	7
"Hyperactive/unpredictable behavior"	6

Ethical issues in qualitative family research

Once interested family members were identified, the investigator explained the purpose of the study and obtained informed consent from the adults and informed assent from the children 7 years of age or older (Appendix A). Langer (1985) has recommended that after consent has been obtained from the parent, children old enough (7 years and older) be given the opportunity to understand the purpose, procedures, and confidentiality of the research. Once informed, children had the right to refuse participation irrespective of parental permission. Two siblings declined to participate even though parents had given permission for them to participate.

The evolving nature of qualitative research and the informal setting in which the research often takes place made it difficult to anticipate all aspects of family life that would be examined as part of the research (LaRossa, Bennett, & Gelles, 1981). As recommended by Field and Morse (1985) and Munhall (1988) ongoing or process consent was employed which involved reminding participants of the research nature of the project and the participant's right to not disclose sensitive information.

LaRossa, Bennett, and Gelles (1981) point out the difficulty of reporting findings of qualitative family research and simultaneously obscuring the identity of families who represent a select population. Maintaining the confidentiality of participants was addressed by the investigator in several ways: tapes and transcriptions were coded with numbers and a list of participants with their respective code numbers was kept in a locked file cabinet; transcripts were reviewed by the investigator, the dissertation committee, and selected nurse analysis consultants whose ethical standards were such that confidentiality of the data was maximized; no names were used in reporting data and efforts were made to camouflage other aspects of the families that might be recognized by someone knowing the family; and tapes and master list will be destroyed after five years. In addition to these measures, the investigator recommended that families themselves not disclose their participation in this study. Even with all of these measures most participating families knew one another and shared their participation in the study with one another. This has been of concern to the investigator who has given considerable thought to how best present the data in a way that does not lose the meanings while maintaining confidentiality. Further discussion of this issue is presented in Chapter VII.

The third ethical concern related to a "blurring" that may take place between the research and therapeutic roles of the nurse researcher. The nature of the questions, the fact that the researcher was a nurse, and the informal relaxed atmosphere of data collection created the potential for perceiving the research experience as a therapeutic experience. As recommended by LaRossa, Bennett, and Gelles (1981) the investigator used an interview format, note-taking, and the use of a tape recorder as reminders to participants of the research nature of the experience. The other ethical concern related to the blurring of researcher and clinician roles occurred in a research experience that became a clinical situation. Two clinical referrals were made with two family members from different families during the course of data collection. In one instance, the number of interviews was limited given the expressed distress generated by participation in the interview process. In the other instance, full interview data and in-home observations were completed.

Data Collection Procedures

Data were collected by the investigator using three strategies: individual interviews, a family interview, and close observation. Interviews were audio taped and transcribed verbatim and field notes were generated from close observations.

All eligible and consenting family members were interviewed individually about their explanatory accounts of autism (See interview guides, Appendix B). In all but one instance this was the first interview conducted with a family member and was designed to obtain information about the family member's explanation regarding the cause of autism, history of onset, and understanding of important treatment strategies; the impact of autism on the affected child; the affect of autism on the family member and the family as a whole; and concerns hopes, and worries about the future. Questions for this interview were adapted from Kleinman, Eisenberg, and Good (1978) and Kleinman (1988).

The Family Coping interview, adapted by Chesla (1988) from the Coping Interview of the Berkeley Stress and Coping Project, R.S. Lazarus and J.B. Cohen, principal investigators, was used to collect data regarding particular caring and coping episodes from adult family members and siblings. The purpose of this interview was to elicit specific instances of smooth functioning and breakdown relevant to the experiences of caring for a child with autism. Family members were asked to describe specific instances in relation to the affected child that they found particularly stressful for themselves, and those instances they believed were particularly stressful for their family. They were also asked to describe specific instances that they found warm or rewarding in relationship to the child with autism. In each episode, participants were asked about precipitating factors, coping strategies tried, alternatives considered, and emotional responses to the episode. and stressful and rewarding episodes that exemplified the individual and family experience of living with autism. Interviews with parents ranged in length from 30 to 90 minutes with most interviews averaging 50 to 60 minutes. Interviews with siblings ranged in length from 10 to 20 minutes each.

Family life experiences provide powerful learning situations which remain a part of human background meanings. Therefore, interview data were collected from parents regarding their personal experiences of living in the world and living in their family of origin that had influenced their parenting and involvement in their present family situations. They were also asked about the responses and involvement of grandparents and other family members with the child with autism and the family as a whole.

The family group interview was conducted with all members of the family who wished to participate and ranged in length from 40 to 90 minutes. This interview was designed to obtain information regarding the view the family presents as a unit about the meaning of living with a child who has autism and the impact on their daily family life. Questions in this interview were organized around what the family typically did together on a day-to-day basis, how responsibilities were divided, the expression of emotions within the family, and individual and family involvement outside the home.

Close observations were conducted to access the day-to-day practices of the family. As Van Manen (1990) describes it, close observation attempts to bridge the distance often created by more traditional scientific observational methods such as one-way mirrors or behavioral checklists. With close observation the researcher attempts to enter the lifeworld of those participating in the study. As the close observer it took time to find a comfortable physical and emotional space within the family. Observations were conducted in the family home, in grocery stores, during summer school, in the home of extended family members, and outside during recreational activities. Observation data supplemented that which was gathered through interviews as well as provided access to the habitual knowledge that was so commonplace that family members might not think to articulate it during an interview. The number of observation periods (excluding interview sessions) with each family ranged from 2 to 5, and ranged in length from 2 to 4 hours each. The time spent with each family including observation and interviews ranged from 10 to 27 hours. The original research plan had called for more observations. The investigator adjusted the amount of observation conducted with the needs, comfort, and availability of each individual family. In one family observation was greatly reduced because the child with autism was generally upset about strangers visiting in the home. In contrast, another family continued to invite the researcher back again and again. The majority of families in the study were receptive to observation and emphasized its importance in understanding their world.

Data Analysis

The purpose of hermeneutic interpretation is to bring to light or make sense of the underlying coherence of a text, making the meaning of the words explicit (Taylor, 1985). For this research, text was generated through verbatim transcription of the audio taped interviews and documentation of observations. Interpretation was an ongoing process between thinking and doing, between the parts and the whole, and between interpretation and substantiation (Benner, 1985; Denzin, 1989; Polkinghorne, 1988). Based on the participants' accounts of their lived experiences, commonalities in meanings, situations, and practices were identified. This interpretive process was enhanced, facilitated, and greatly dependent upon interpretive sessions undertaken with the cooperation of colleagues who were willing (at various phases of the research) to read transcripts, make interpretations, ask questions, and push my thinking and reflection. Identification of themes, exemplars, and paradigm cases were the three strategies used to interpret the text.

Thematic analysis involves the identification of recurring experiences, concerns, emotions or other topics expressed by the participants. Several levels of analysis were undertaken to search for themes. Initially, each transcript was read several times in its entirety so that the contextual and situational aspects of the story were left intact. Interpretive notes were made of the salient aspects of the transcript. Once 4 or 5 interviews had been completed related to particular aspect of the study, such as the explanatory model interview, a preliminary coding system was constructed based on questions from the interview guide and emerging themes from initial interpretive analysis. Coding categories served as a data management strategy from which further interpretation of recurring themes took place. Salient background meanings, concerns, demands, stressors, coping strategies, and family history were interpreted in order to identify family patterns of caring. The 39 codes developed and used in the study are presented in Appendix C.

A paradigm case is a strong instance of a particular pattern of meanings (Benner, 1985). Early in the process of interpretation the researcher may recognize a particular pattern of caring or family involvement (or whatever the focus of study is) without understanding what the pattern represents or why it seems to stand out. Paradigm cases can serve as markers for further identification of cases with similar global characteristics. In their report of parental experiences of caring for blind children Kodadek and Haylor (1988) identified four paradigms of family caring: the realistically accepting family, the perfect blind child family, the overwhelmed family, and the devoted parent family. The meaning of the child's blindness, concerns for present and future goals for the child, agreement in parenting style, and relationships with extended family and outside agencies were different in each of these paradigms and produced different patterns of caring. Paradigm cases were identified in this study although they are not included in the final report because confidentiality of participant families could not be guaranteed.

Exemplars are smaller than paradigm cases and as with paradigm cases exemplars are instances of particular patterns of meanings (Benner, 1985). An exemplar is a story about a particular transaction in which the meaning of the situation is maintained. Exemplars are used extensively in the following report to substantiate the interpretations of all aspects of family caring.

Articulating the process of interpretive analysis is challenging and Figure 1 is an attempt to capture the essence of the process in diagrammatic form. The interpretive process begins with the reading of transcripts and proceeds through the steps outlined. At any point along the way themes, exemplars, and paradigm cases may be identified which then influence subsequent interpretations. The importance of Hermeneutic reading, reflection and writing as described by Van Manen (1990) are essential

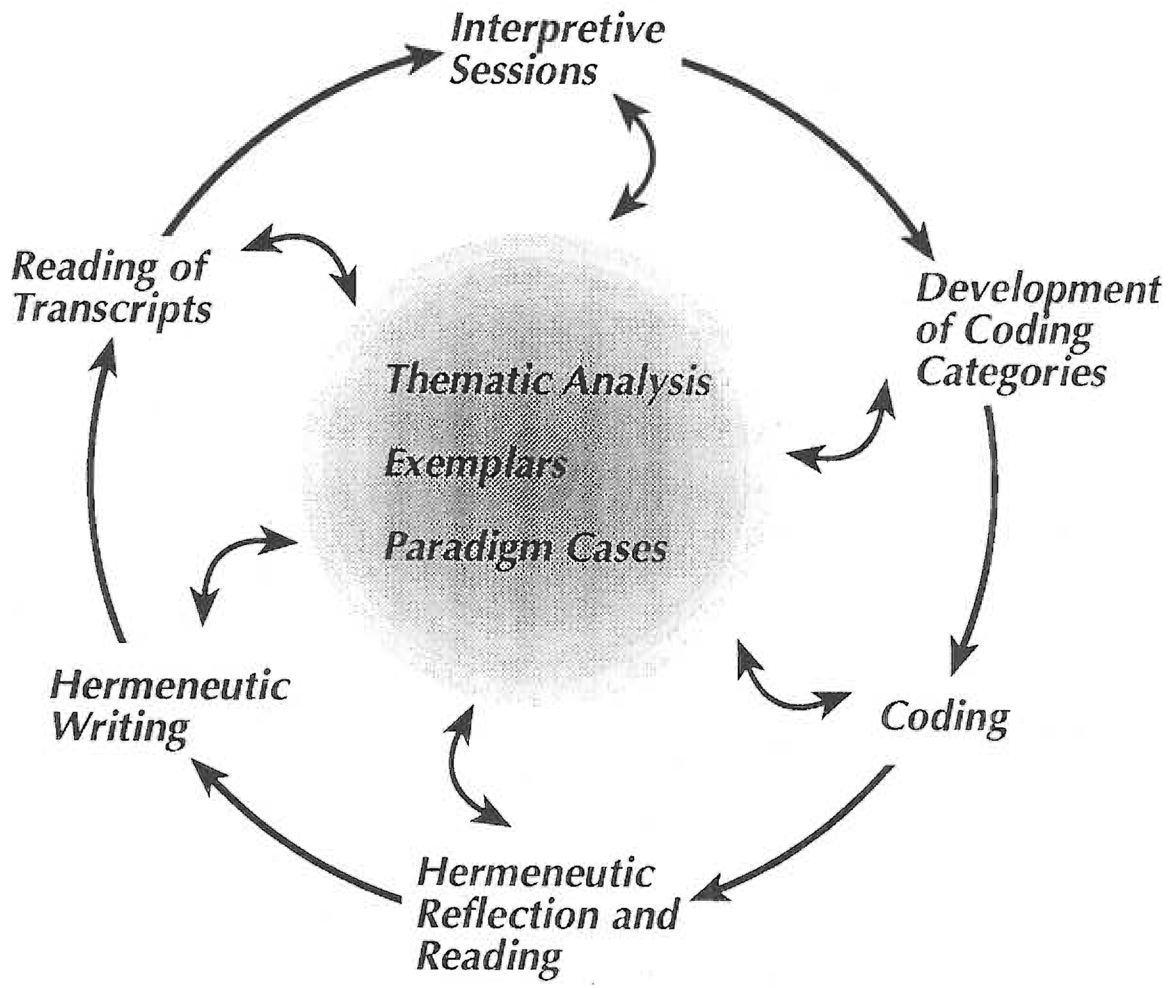

Figure 1. Interpretive analysis process

aspects of the process. Through the writing and the rewriting the investigator is simultaneously distanced and brought closer to what she knows about the phenomenon of interest, the lifeworld of those studied, the relationship between the abstract and the concrete, the universal and the unique lived experience, and the objective words about the subjective experience of the researcher.

Scientific adequacy in interpretive studies

Just as it is imperative for the researcher using quantitative methods to attend to issues of scientific rigor, so it is with the qualitative researcher. For the quantitative researcher scientific rigor is addressed by strategies designed to enhance validity and reliability. Lincoln and Guba (1985) have described these concerns regarding scientific rigor in qualitative methods as issues of 'trustworthiness.' Specific measures designed to address the scientific adequacy of this study are described in four areas as suggested by Lincoln and Guba (1985): credibility, known as internal validity in quantitative studies; transferability or external validity; dependability, or reliability; and confirmability, or neutrality.

Strategies intended to address threats to the credibility of a qualitative study are based on the assumption that multiple constructions of an experience are possible. From that assumption the qualitative researcher must collect data in a manner that enhances the possibilities of describing those multiple realities (Lincoln & Guba, 1985). Prolonged engagement and persistent observation provided the opportunity for the researcher to access the scope and depth of caring in families of children with autism. Data were collected from multiple members of the family, using multiple methods, and underwent several levels of analysis from different interpretive consultants. In the process of ongoing data collection the researcher shared initial interpretations with participants providing the opportunity for families to respond to the interpretations. Sandelowski (1985) identified the potential enmeshment of the researcher in the lives of those she studies as another threat to the credibility of the research. In this study, the researcher had regular debriefing sessions about her involvement with the study families with a mental health clinician.

The responsibility of the qualitative researcher is not to establish the transferability or generalizability of the research findings. Rather the qualitative researcher must provide access to the data base from which another individual may judge the transferability or fittingness of the findings (Lincoln & Guba, 1985). In order to provide an adequate data base, appropriate sampling strategies and the collection of thick descriptions of the phenomenon of interest are measures to be taken to address the fittingness of the research. In this study purposive or theoretical sampling was used by collecting data from those most experienced in living with a child with autism, various family members. A limitation of the sample in this study is that all the children with autism were males. The ratio of boys to girls affected by autism is 4:1 and therefore this is a relevant sample; however, the stories of families of girls affected by autism is probably different. Study families were constituted by individuals with a economic, employment, educational, religious, and cultural diversity adding depth and variety to exploring family caring. Detailed accounts of explanatory accounts of autism, caring episodes, family history, and daily family life designed to preserve the historical, cultural, and situational context of caring provided the thick description used for analysis in the study.

Dependablity or auditability refers to the consistency of qualitative findings (Lincoln & Guba, 1985). Triangulation of data sources, data collection methods, and analyses as described above under credibility also contributed to the dependability of the findings. Lincoln and Guba (1985) and Sandelowski (1985) recommend maintaining an audit or decision trail to address concerns about dependability. In this study, the researcher kept track of interpretive sessions and the evolution of coding strategies for changes in understanding. These notes are saved for future reference and further reflection. The goal was to provide enough information and detail about the study that another researcher could arrive at comparable although probably not identical results based on the data base provided.

Confirmability, analogous to the concept of neutrality in quantitative methods, relates to the concern for investigator bias. In quantitative studies, researchers may attempt to limit their bias by insulating themselves through such measures as standardized instruments and statistical analysis. In contrast qualitative researchers attempt to minimize the distance placed between themselves and the study participants. Each comes to the phenomenon of interest a unique cultural background making it impossible for the researcher to fully enter the world of the other. Maintaining an audit trail and the researcher's debriefing with a mental health clinician were measures taken in this study to address the issue of confirmability of the findings.

CHAPTER IV

Results

Personal and Social Meanings of Autism

A central concern for nursing is to help individuals and families cope with the stressful aspects of illness. The purpose of this chapter is to describe the ways in which family members "made sense" of autism for themselves. Family members also described their perceptions of how other significant persons in their lives, namely health care professionals, and the lay public seemed to interpret the symptoms of autism expressed by their child.

The purpose of articulating and interpreting explanatory stories of autism is to facilitate the nurse's entry into the family experience of autism. Kleinman (1988) proposes that by entering the emotional, cognitive, and perceptual everyday world of the family the clinician is able to witness empathetically the experience from the family's perspective. A phenomenological entry into the lived experience of families becomes the basis for nursing care of the family. Such care includes but is not limited to facilitating the interpretation of change and progress, initiating and supporting meaningful and appropriate interventions, and understanding what the family needs to know and how best to help them gain that knowledge.

Kleinman (1988) makes distinctions between disease, illness, and sickness. Disease is a term that is based on the practitioner's assessment of a problem, which in this instance means autism. Illness refers to the human experiences of having the disease. The illness experience is relational in that it takes place within a life trajectory of an individual and family. As such, it is not only the experiences of the person affected by a condition but also the experiences of those closest to him or her. Sickness is the universal understanding of a condition as it relates to the broader economic, political, and institutional structures within the culture. Each of these terms is relevant in understanding the cultural and situational context of caring for children with autism. While the implications of each of these terms will be addressed throughout the chapter, this section will address specific aspects of the personal and social meanings of autism assumed to be important to understanding the individual and family illness experiences.

The question to be addressed here is how individual family members make sense of autism. Specifically, what are the family member's explanatory accounts regarding: (a) the cause, the way in which autism was expressed in the child, the severity, treatments and care believed appropriate; and (b) family members' hopes and concerns about the trajectory of autism and their perceptions of the impact of the trajectory on the future of the child and family. The following is a description of individual family members' understandings of the cause of autism and how these background beliefs provided the basis for treatment and for the approach to certain aspects of care within the family. Hopes and concerns about the future tended to be universal across families and less dependent on the explanations of autism. Therefore, the discussion about family concerns about the future follow that of the causal model and care. Once these family explanatory accounts have been presented the health care professional and social-cultural understandings of autism explicated in the narratives will be described.

Explanatory Accounts of Autism

Each family member interviewed had a uniquely personal understanding of what she or he believed caused autism in the child. Most family members incorporated more than one possibility into their explanations of the cause, often reflecting knowledge of the current scientific understanding of etiology. The degree of bafflement about the cause of autism and the importance placed on understanding the cause varied considerably across participants and within families. All parents had been told by a professional at the time of diagnosis that the cause of autism was unknown and that the current scientific consensus is that most likely there are multiple causes.

All participants identified at least some organic component to the child's autism, although the organic cause was not always the primary explanation upon which care and treatment were based. None of the family members in this study believed their child's autism had been caused by non-responsive parenting, a theory that guided early research and clinical interventions (Kanner, 1943). However, one parent did not discount this theory as a possibility in some children, although not her own.

Four causal accounts of autism were identified, two of which were solidly embedded in organic explanations, and two that were not. Each explanatory account is presented and includes a discussion of the beliefs about what caused autism in their child and rationales supporting the beliefs, the extent to which family members thought about the cause or tried to make sense of their child's behavior, their view of the child throughout infancy, the interpretation of the child's every day behavior, and the type of treatment strategies pursued and the decision-making around the pursuit.

Autism is a permanent organic condition

Cause and rationale. Eight family members (5 mothers, 2 fathers, and 1 sibling) believed that autism was the expression of significant organic impairment and that spontaneous resolution or identification of a complete cure was unlikely in the near future. Organic causes identified by family members were complications of pregnancy and labor and delivery, genetic transmission, biochemical disruptions of the brain, hearing hypersensitivity, and severe reaction to a childhood immunization. These family members believed that autism would always be a significant part of their child's world. However, this did not in any way mean that the affected child could not be helped. Family members shared their reflections about particular events, scientific literature, practical knowledge of other persons affected by autism, and observations of their child's way of being in the world as the basis for their beliefs about the organic and permanent nature of autism.

Early life of the child. As they reflected on the life course of their children parents believed that their child had been different since birth or early in infancy. This awareness of the inherent differentness of their child with autism came only after time and through reflection. Mothers (N=5) talked about the experience of being so involved in caring for their child that they failed to pick-up on or explained away the infant's way of being in the world, or care demands that exceeded those of their other children.

> He was difficult to make a connection with. He was. Looking back on it now, if I had known then what I know now, I would have been able to diagnose it (autism) when he was just a newborn. He was so stiff when he was a newborn...he didn't smile until he was seven months old, and that was his first social smile and that took a lot of work (on my part) I realize now.

Everyday world. The child's every day behavior was interpreted by these family members to be expressions of inherent inabilities of the child to communicate his needs, desires, thoughts, and emotions.

> ...cheeseburgers can't have cheese hanging out but they have to have cheese. Like when we go to Burger King or something we have to cut it all the way around the edges so there's no cheese hanging out. And we have to take the pickles out, but if we get it without pickles he won't eat it. You have to take the pickles out in front of him. I know he's a little bit spoiled but he doesn't...I don't think he wants those little pieces off the sandwich just because they're there for no reason, because they annoy him. There's something in the texture of it (and how he experiences it).

Another parent described her thoughts about how her son experiences the every day world:

> I just slowly over the months...watched him and I saw how he had all these senses and he didn't sense anything right. He didn't smell right. He didn't feel right. He didn't hear right. He didn't see right. He doesn't know where his body is the same way. He senses everything differently.

Several things stand out about these excerpts. First, these parents do not blame their child or believe their child has control over his unique way of experiencing the world. Second, the child's behavior is attributed to an inherent disability in him, not to a failure of medical management, inadequate discipline, or other possible influences. Third, there is an assumption and central understanding of the parent that the child is different and requires different approaches to parenting.

Importance of knowing. One of the characteristics of the parents in this group was the intensity of thought and reflection that had been given to the notion of what had caused autism in their child. Not all parents were currently involved in this intense reflection but the narratives suggested that the importance of knowing what caused autism in their child had been a significant part of their stories in the past. Review of the pregnancy experience or reflection on scientific literature were the two areas most often discussed. The intensity of thought was reflected in the narratives in that these discussions were often very detailed and demonstrated tremendous work at understanding the medical and scientific literature. In the following excerpt, a father shared his reflections about the cause of autism and the analogies he sees between autism and diabetes.

> With diabetes we understand it's a lack of insulin, but with autism, we don't know what it's a lack of. And whatever it is, it's responsible for a whole lot of mental functions. Whatever the protein is. Whatever the brain function is, I think it has a biochemical base to it... And my guess is that it's a failure (of) genetic expression. It's like the genes... each gene in the body is supposed to produce some kind of function. And the DNA contains all the plans for how your body's going to build and operate itself. And it also has a certain timing mechanism... I think that perhaps when you're about 18 months something's supposed to go on. This one gene or whatever it is, is supposed to turn on and produce this chemical. And in autistics it just doesn't turn on. It's a failure. It could result from miscoding...like a faulty copy of a certain segment of the gene. Like one little nucleotide is out of place and the whole thing's all screwed up and it doesn't produce that chemical.

An intense review of the pregnancy experience was described by two mothers who viewed autism as a permanent organic condition. It is possible that women in the study who held alternative explanatory accounts of autism also reflected on their pregnancy experiences; however, a pregnancy review did not show up in the narratives as a significant part of their story. The central concern of this reflection seems a bit different than the question of "what caused autism?" or the importance of knowing what caused autism. The question of central concern for these two women was "did I do something (or not do something) that resulted in my child having autism?"

> IN: So what do you think caused his autism?
> MO: You mean, what do I really think?
> IN: Yes.
> MO: Well, it could easily be genetically linked because I have a cousin who's 47 and he must be autistic. He must be... (but) during the time I was pregnant, I wasn't just afraid, it was beyond fear. And from the one time we saw Dr. X until the next time we saw him, he dug out this research that talked about these different hormones that are released when mothers are under a certain kind of stress, and that it does cause birth defects. And that's what I think did it.

For both women, self-blame and blaming others were significant parts of their stories as they revealed their beliefs that complications of pregnancy were central to understanding the cause of autism in their child. For one mother, the guilt has resolved and for the other, alternative explanations had begun to emerge supporting Kleinman's (1988) contention that explanatory accounts are dynamic and evolutionary in nature.

Treatment and care: Autism is a permanent organic condition. The goal of treatment strategies in this group was to promote optimal growth and development of the child given his limitations.

> (I think my son should have) only that which makes him manageable. Because my attitude about intervention and treatment is that it's not going to cure him.

The types of strategies sought out and pursued were fairly consistent in this group and included speech therapy, sensory-motor integration, special education, behavior management consultation in the home and school, and an experimental intervention designed to desensitize the child's perceptual hearing problems. Many families were involved with three or more of these treatments simultaneously.

Parents most often used the advice of other parents and their own abilities to sort out what were the most appropriate treatment strategies for their child in deciding which treatment to pursue.

> We've more or less had to find (appropriate intervention) out on our own. We didn't have somebody to say, to sit down with us and say, "Well, here's autism and here's (your child), and this is what (your child) is doing and this is what he is going to be doing and this is how you handle it." It took a long time and a lot of reading and talking to different people, other parents, to get what I consider the picture that I have now which will probably be more refined as the years go by. But it took a long time. It took a year, at least a year.

Two mothers believed they had received helpful advice from various health care professionals but more often health care professionals were viewed as skeptical barriers to identifying interventions, leaving parents doubtful about their own parenting abilities.

Parents gave thoughtful consideration about which interventions to take on.

> But if anybody makes claims that it's going to significantly lessen his autism, or that it's close to a cure, miraculous or something like that, I'm very skeptical. I know there's a lot of people out there that think they can make a few easy bucks by pushing a treatment that appeals to your beliefs or your hope, that in fact from a scientific perspective may not have a whole lot of merit. So, I don't think I'm anybody's dummy.
>
> Then there's some other parents on the other side that think it's food allergies, and they do these other things. And some of them do the craziest things, you know it's quack(ery).

Parents also thoughtfully considered which interventions required a complexity and intensity of involvement that was beyond the capacity of the parent or family to provide.

> (Some interventions) are hard to maintain because there are so many other things. You've got your own life. You're tired, you come home...it's not like Ozzie and Harriet in the TV show where you've plenty of time to do everything that you want.

The point is, parents in this group had what might be called a discriminating approach to treatment and care. They involved themselves in the process by gathering information from many different sources and made decisions about what to pursue based on the scientific merit of the treatment, what "made sense" to them, the recommendations of professionals, and the demands placed on the family.

Autism is an organic disease process

Cause and rationale. Parents who viewed autism as an organic disease process believed that autism was a medical condition for which medical treatment could improve or cure their child. Both parents in this group were mothers and they shared the same belief about the cause of autism in their child: Allergies (or allergies and chronic systemic candida infection) created biochemical disturbances in the brain resulting in impaired communication, behavioral outbursts, and disturbances in the ability to relate to other human beings. The disease aspect of autism was well integrated into the explanatory accounts of each mother.

> ...as the child gains more control and has fewer autistic tendencies they tend to refer to them as residual. And so it gives you the feeling or the effect that at one time there was some kind of a medical process, or a disease process that was in full swing...I consider him to be physically ill. I do not consider him to be brain damaged, genetically damaged, or psychologically incapable of making a recovery.

Seeking medical treatment had been pursued because through mass media or parent publications they had learned of other children previously diagnosed as autistic who turned out to have had allergies, and whose autism was relieved or cured through appropriate treatment. Based on their practical knowledge of their child and knowing his ways of responding to the world they saw similarities with the other children and decided to pursue alternative medical interventions.

Early life of the child. In contrast to parents in the previous group who viewed the child as different from birth, the mothers who held a disease process explanation described a normal newborn and infancy period with a gradual developmental decline between 12 and 36 months of age. When asked about severity, many parents considered multiple aspects of the child's present abilities in responding. These mothers considered multiple aspects of the child's abilities currently as well as emphasized the child's progress since the initiation of medical treatments.

Everyday behavior. Symptoms of autism experienced in everyday life, such as hyperactivity, tantrums, and decreased responsiveness to the environment were interpreted as episodic responses to the child's exposure to allergens or inadequacies of the medical regimen.

> And so, if we would screw up and forget to give him a dose of his medicine, or we would feed him something he shouldn't have had, we'd be back to stage one momentarily. Or we would certainly go backwards and then it would take us a few more times to catch back up and get things even yet. And we're not having that difficulty now that we've changed to a stronger medication. But, we trialed him off of his amino acids when we've run out, and it's like we go downhill again.

Importance of knowing. As with parents who viewed autism as a permanent organic condition, both of these mothers had expended a great deal of time and energy in thinking about the cause of autism in their child. Identifying the cause of autism was extremely important because once the cause could be identified appropriate treatments could be pursued. Making sense of autism based on a disease process model evolved out of reading and listening to the experiences of others, and the fit between what they came to know and their observations and experiences with their child.

Treatment and care: Autism is an organic disease. One of the primary focuses of care was to identify appropriate medical interventions for the child with autism. To some extent all families in this study had frustrating, stressful, and occasionally devastating encounters with health care professionals. Learning to manage these encounters was part of the parenting work expressed by most parents. However, the narratives of those with the disease explanations were heavily laden with stories of conflicted interactions with health care professional as parents struggled to have their initial concerns or alternative ideas for treatment (i.e., treatment outside recognized standard medical practice) taken seriously.

> First you have to find a doctor that will listen to you and not call you some kind of a charlatan. If I am successful at finding someone to treat him, then I think we'll probably make it through puberty moderately okay.

> (During visit to pediatrician's office to get a referral for sensory-motor therapy)...he didn't really comment except he kept saying, 'Do you want me to comment on what you're doing? And (to me it felt like he was saying) 'I really want to tell you that I don't approve of what you're doing.' And I kept saying, 'No, I really don't want you to comment. I just wanted to inform you of what we're doing.'

These mothers understood the importance of having the medical community be supportive or "on your side." When the support was not available or when parents and health care providers held different causal accounts of autism, parents were left to fend for themselves as they pursued alternative medical interventions for their sons. Because of encounters with health care providers such as these and parental pursuit of alternative medical interventions, parents had to spend considerable time and energy making their case for why they believed and did what they did and they had become strong advocates for their positions as well as for their children based on the medical cause of autism. Because they found so little "professional" support, these mothers stand out not as partners in care but as the sole providers of care.

> A lot of the reason I feel there's room to work with him is because at 7 I did get started on some kind of medical intervention. I started him on the vitamins and I started him on the minerals and I started him in the allergy treatment. ...I feel like I'm on the right track. And I don't care what anybody else says. They can sit and watch. If I go down in flames, well at least I tried. Nobody else is trying. At least I'm trying something.

The emotional and physical demands of being the unsupported primary health care providers for their sons has taken its toll .

> I think I had probably the worst case of anxiety over disentangling myself from him, because you don't trust anybody. You don't trust the doctors. You don't trust the teachers. You don't trust the administrators. You don't trust anybody. It's pretty doggone bad when you can't trust anybody to leave the child long enough to go take a shower. (My son) had to be asleep before I could go take a shower. I know there are many descriptions of this in the psychological and psychiatric journals, separation anxiety. Yeah, I had a real good case of it.

> (Following an episode where a child stepped on a nail and his mother had to contact several different health

> care facilities to know how best to proceed) The only person who seemed to comprehend was our pediatrician and she had never seen (my son) before. I only just talked to her about it. She's wonderful. I'm just so excited. And I'm hoping that she's going to be able to kind of manage our health care. Because I feel like I'm managing it. And we're going here for this and there for that, and I'm tired of all this runaround and nobody knows what the other person's doing. And I have to keep explaining it to them. And it's such a BURDEN.

These two mothers involved themselves in treatment based on a disease model of autism. From the narratives one can interpret that some but not all of the physicians they encountered have been operating under a different causal explanation of autism, one that is not compatible with the disease model. This meaning gap generates different concerns as a focus of care. From the parental perspective, exploring a number of alternative treatments was a central expression of caring. Although this study did not produce data from physicians, one can speculate that they may have been concerned about encouraging involvement in non-scientifically based interventions. From the viewpoint of the parents, the reluctance of physicians to support parental pursuit of alternative treatments was perceived as failure to recognize the importance for doing everything possible for their children.

Autism is competing explanations

Cause and rationale. A third group of parents (3 fathers, and a 4th by inference from mother's data) are described as entertaining competing causal explanations of autism in that their narratives were characterized by vagueness. In one sense the explanations of three of these fathers were vague in that the depth of understanding about autism was markedly less when contrasted with other parents. The fourth father in this group had a very deep understanding about autism, but was vague about committing himself to any certain explanatory account relevant to his own child.

For two of these fathers the competing explanations came from considering different possible organic explanations, such as genetic transmission, hearing sensitivity, allergy, Tourette's Syndrome (a neurological disorder), and vitamin deficiency. Some of these possibilities are consistent with current scientific thinking about autism and others would be considered outside of mainstream Western science.

> ...there's eight types of autism and I think the one that he's got has to do with the hearing (based on an article read in Reader's Digest). We'll find out after August because that's when he gets the (experimental) treatment. And maybe there's chemical things in there too because my mother had Alzheimers which has to do with serotonin levels and this serotonin is mentioned in his disease somehow. So between the serotonin and the hearing sensitivity, maybe between the two of them, that has something to do with it. Maybe it's hereditary. But since the doctors don't know, I'm sure I don't know, it's just guess work too.

For the other two fathers the competing explanations were between organic causes versus a spoiled undisciplined child.

> And what I know about autism is that something in the brain...is just not...I really say, in the eight-cylinder mode, one cylinder isn't really plunking real

> good... His physical problems that he has, I understand... But his discipline and the way he does things needs to be firmed up on the other end (my wife) still. You can't treat them like they have a disease. When there's nothing wrong with the little boy except that he just doesn't process information like everybody else does. It doesn't have nothing to do with discipline (autism). If he's wrong, he's wrong.

The rationale for these competing explanations was based in a partial understanding of the disease, as Kleinman (1988) uses the word, and less of an understanding of the illness experience of their child and themselves as his parent. Fathers who had limited understanding of autism had obtained what information they did have from what they had heard from others. For the father who was vague about committing himself to a particular causal explanation about his son, the rationale for doing so rested in an acceptance of the current scientific understanding of autism, which is by nature extremely vague and full of uncertainty.

Early life of the child. Fathers in this group had experienced varying levels of involvement with their sons since birth. Two believed their sons to have been well developing children as infants, while the third saw his son's behavior as different very early on.

Everyday behavior. Everyday symptoms of autism were often mysterious to these fathers. Given the competing causal explanations, everyday behavior had many possible interpretations. One father exemplifies the nature of the work involved in interpreting the child's behavior when one has competing organic explanations.

> One of the things that (my son) does right now is his high "EEE" shriek. We're still trying to figure out what that's all about. I mean, is it 'stimming?' Is it a panic-nervous disorder? Is it him just sort of stuttering, trying to say something? What is it? A thought I've had is, is it Tourette's? Or a kind of verbal tic? We don't know.

For the child with autism whose father held competing explanations of autism as organic versus lack of discipline, his everyday expressions of autism were interpreted as misbehavior.

> (A mother describes her efforts to tell her husband about how their son likes to have his sandwiches cut preventing a tantrum). I tried to explain this to (my husband). And he said, 'You don't know everything.' And he'd cut the sandwich and sit down and (my son) would go into a tantrum, and then (my husband) would get real upset, and say 'Well, this kid's just crazy. I don't know what to do with him.'

Importance of knowing. What seems different about this group of parents is the extremeness with which they thought about or pursued knowing about autism. For one father in this group autism was a sad mystery and he had obviously spent a great deal of mental effort in trying to solve the mystery. In contrast, for the other fathers in this group understanding the disease or illness experience of autism was an absent or secondary aspect of their involvement with autism, and seemed less important to them when contrasted with other parents.

As with the mothers who had reflected intensely on their pregnancy experiences, the fathers in this group had also reflected on their actions they considered relevant to the question "Did I do something (or not do something) that resulted in my child having autism?" After 9 years a father still lives the experience of his son's birth and how his own actions may have contributed to his son's autism.

> There was a very funny instinctual feeling I had the night of his birth, like they were going to try to deliver him wrong...They wanted to give him a circumcision, which I still don't believe he needed. And they just wanted to do so many things to him and I just felt so guilty by leaving there. I still feel to this day that I should have taken him home with me. Something was wrong by me leaving him there. It's really a gut feeling like I KNOW I goofed by leaving (my son) in that little tank there. I just KNOW that I should have gone and said, 'He's coming home and there's nothing you can do about it.'

Autism is competing causal explanations: Treatment and care. In those families where fathers held competing organic causal explanations, children with autism were involved with numerous therapeutic interventions including special education, speech therapy, vitamin therapy, allergy treatment, and an experimental audiology treatment. The goal of treatment was to find a cure or to place the child in the best possible physical condition for future scientific discoveries, and mothers took the lead in identifying and procuring interventions. This is not to say that these fathers were uninterested or uninvolved but rather they were supportive of their wives' efforts rather than actively involved in the process.

Interventions for those children whose fathers had competing causal explanations of organic versus undisciplined child were both involved in special education, and one of these children was also receiving speech therapy, with mothers again taking the lead in identifying and initiating relevant treatments. The fathers in this group seemed to view discipline as the primary intervention needed and saw little need to seek outside resources.

> If we can control him and work ourselves to where we're controlling him (providing better discipline) and keep him in a certain line. Medication is not the answer, surgery isn't the answer, nothing is the answer. But, good old wholesome working out the problems yourself and try to work on them, unless all else fails and then you have to go do it (seek outside help).

A common underlying theme that runs throughout the narratives of these fathers is the attempt to normalize either their response to having a child with autism, normalize the child or normalize the parenting strategy to a difficult situation as demonstrated in the following exemplars:

> Sometimes I have to be very watchful of (my son) [age 9 years]. I'm continually feeling that I have to be kind of on track, what is he up to? Not that I don't think any father or like normal parent wouldn't have some amount of that being on track, but I feel that I have to be extra on track.
>
> When we're out and about 99 percent of the people don't realize he's autistic. And when he speaks I want the other remaining, well at least one-half of that one percent that's left to think that he's not autistic also, when he speaks.
>
> (When we've been out in a restaurant eating) I've caught him licking the table. You'll be eating and he'll crawl underneath the table and start crawling around, making silly nonsensical words and calling people names and these words that don't have any meaning. You know, just acting silly and goofy... I tell him to straighten up and sit down and try and control himself... that's when he gets very nervous, looking around.

There is no one way to interpret this explanatory account of autism and its relationship with caring practices designed to normalize the experience. Normalizing the experience of having a child with chronic or handicapping conditions has been described as a common and healthy coping strategy among parents (Knafl & Deatrick, 1986) and is one often recommended by clinicians. However, in each of these fathers, understanding the central concerns, background meanings, and personal histories of each father, each of which was different, provides much more insight and a basis for nursing care than does the concept of "normalized care."

The observance of this explanatory account could serve as a clue to the nurse that there are other underlying issues that need to be addressed. If the attempts to normalize the experience fail to recognize the innate differences of the child or the situation created by the child's condition, the potential for parenting and family breakdown is increased. If the attempts to normalize care are based on an inadequate or incorrect understanding of the disease and illness experience of autism a nursing strategy designed to address the disparity might be in order. If the vagueness is related to an unresolved sense of parental guilt of a well informed parent, an educational strategy would not be appropriate. What seems most important here is to understand the meaning or central concern behind the competing explanations.

Autism is a religious experience

Cause and rationale. A fourth group of parents (1 mother, 1 father--not in the same family) had explanatory accounts in which religious implications were more than casual considerations. Although each parent incorporated organic causes of autism into their explanations, the religious possibilities were also salient aspects of their stories. One of these parents at times believed that her child was possessed by the demon, while the other believed himself to be the recipient of God's intervention.

> What we believed happened (was that) the ear infections caused his mind to instead of grow, (to) live in the past, and just kind of stop (while) his body continued to grow. But his mind didn't continue to grow and depression sunk in...So, what I thought when we heard about the word autism is that... God was punishing me by giving me (my son). And still I had thoughts about that for a really long time, every once in awhile it'll still pop up.

The rationale for this causal explanation was found in the personal background meanings of each of the parents. Involvement with their respective religious beliefs was a central part of their lives. Tangible aid such as information about autism, assistance with the child, recreational activities for all members of the family and spiritual succor such as finding the strength to carry on, and hope for the future were available through ongoing involvement with their churches.

Early life of the child. Each of these parents had very difficult experiences with their autistic child during the child's infancy and early childhood. The expression of autism in both of these children had been experienced as very demanding on the family.

Everyday behavior. For the most part each of these parents attributed their child's communication difficulties and behavior problems to the organic nature of autism. The underlying theme for each though is that God or the Devil also had a purpose. For one parent, the child's behavior was viewed as an ultimate test of patience and understanding and there was an ongoing challenge to rise to the occasion. For the other parent, the child's behavior was interpreted at times as an organic problem aggravated by the work of the Devil.

> Something in the brain that doesn't work right. Maybe it's a chemical imbalance, I don't know what causes it...He has days when he's just the sweetest little thing. And then other days it's demon possessed. I actually thought he was.
> IN: Did you?
> Oh, yes! I still think so sometimes. You would have to see him when he has one of his fits. He looks wild. Oh, he screams and cusses and... just destroys things.

Importance of knowing. The desire to know what caused autism or what the current scientific thinking was related to autism were not salient aspects of the narratives of these two parents. At this point in time, these parents either expressed a sense of relief that they were not the cause of their child's condition or were working hard at being involved with their child in such as way as to meet the spiritual challenge presented to them.

Autism is a religious experience: Treatment and care. Both parents had strong religious belief systems and being involved with church was a major part of their involvement with the world. Each had sought out the help of the church and tried religious cures for their child. In the following excerpt the initial search for help through the church is described.

> What the hell do we do? And how do we cope with this? So, we did the best thing. We got in touch with the church that we were going to and we just got into it. Well, the trouble is that the church didn't want to handle it. Although they tried healing (our son), anointing him with oil and praying over him, they did that. They just really did not want to seem to get involved really helping him (on a weekly basis at church).

The church does not play a central role in the ongoing care and treatment of this child, although it remains a significant support system for the family.

The diagnosis of one of these children had been made only 6 months prior to the family's participation the study, and educational placement in a special behavioral classroom was the extent of current treatment strategies. There was expressed concern from the parents that the behavioral classroom was not the best for their son but they were waiting for the school's reevaluation of their son's educational placement. Information obtained from the religious radio station had prompted the mother in this family to consider pursuit of allergy treatments for their autistic child. In addition, the use of prayer and the anointing of oil were important aspects of caring.

> Now I (pray) a lot (with him) when he gets real frustrated. And a lot of times, it helps. It does. It calms him right down. I believe in the power of God. I really do. I've seen it with my own eyes with (my son). I've seen how it's affected him. He still can be very hard to handle but he has changed so much in the last couple of months. He's gotten easier to handle because of the fact of when he's sleeping, I anoint him with oil and I pray for him. I pray for both of my children a lot. And also (for) me. I've had more patience with him.

Common experiences

Examining each explanatory account in detail lead to the identification of several experiences common to many parents. Without regard to any particular illness explanation of autism, many parents experienced self-blame or self-review related to the diagnosis and a slow process of coming to know that their child was experiencing the world differently.

A case could be made for identifying self-blame as a separate explanatory account of autism, that is to say that a parent might see themselves as the cause of autism. Because self-review or blame was a common experience of many parents, it seemed more appropriate to discuss it as a personal care demand and is described and elaborated upon in the section below related to the personal impact of having a child with autism. The intense reflection given to the cause of autism perhaps is best understood in light of the fact that parents must deal with the notion that their child has a condition for which there is no known cure and no definitive intervention. The difficulty and unwillingness to passively accept that there are no certainties in autism in a culture that values cure and a high tech approach to health care was a recurring theme among parents who held a variety of causal explanations of autism.

These data also exemplify the transitional nature of coming to understand that a child is different. Parkes (1971) describes a transition as a change in the assumptive world. In this study, family members had to move from an assumptive world in which their child was a healthy, normally developing child to an assumptive world in which their child was communicatively and developmentally disabled. The subtleness of this transition that many parents experienced is exemplified in the following exemplar.

> I've talked to other mothers about this too, you just accept your child the way he is. You don't really think of him as particularly different or even disabled or anything. He's just (your child).

With the passage of time and the failure of their child to achieve significant developmental milestones parents came to know that their child had problems, although the exact nature of the problems was not initially interpreted as autism. This evolutionary nature of coming to know that your child has autism is consistent with the work of Kodadek and Haylor (1988) who described the experience of diagnosis in parents with a visually impaired child as either a "dawning awareness" or a "sudden awareness" experience.

Dawning awareness referred to the gradual awareness of cues from the child and the ability of the parent to integrate these cues as signs of deviance from the expected behavior of their child.

The Unpredictability of the Future

The experience of autism is historically situated, not only in the experiences of the past but also in the hopes and concerns about the future. The unknown trajectory or course of autism in the child, lack of available community resources, and societal and cultural intolerance and rejection of persons with disabilities provided the basis for an uneasy state of uncertainty and apprehension in family members. Concern for the child and concern for the self in anticipation of potential long-term care provided the structure for talking about the future. How family members lived their lives in anticipation of the future and for putting the child with autism in the best possible position to face the future was also a significant part of the family story.

Parents had two central concerns about the future: 1) a desire for their child to lead as normal a life as possible; and 2) a desire that the child's dependence on others be minimized. Regardless of the severity of autism, parents wanted their child to have a meaningful life. What this meant was that family members wanted the child to have a job, perhaps live in an assisted residential facility or, if capable, live on their own. Parents wanted their children to have friends, go to dances, and ride the bus.

> I would like him to have pretty much what other kids his age and growing up would have. The same frustrations and the same experiences. Dodge the draft or join the army, whatever you like. Have a job. Have a girlfriend, or a boyfriend if he was so inclined. But knowing what he wants and getting it... Knowing what he wants and getting it.

Parents cited a number of reasons for concern about their child's need to be reliant on others outside the family. Many of these concerns are addressed below under the cultural context of autism. However, a father sums up the concern with the following:

> What I don't want him to be is at the mercy of other people's kindnesses or unkindnesses.

Trajectory of Autism

Making it. In every instance, parents talked about the possibility that their child's autism might resolve, either spontaneously or through interventions. Parents referred to this resolution as "making it." Although statistically the possibility of "making it" are extremely small, approximately 1 to 2 percent, every parent to some degree maintained this glimmer of hope. One father believed without a doubt that his son would 'make it.'

> It'll (autism) get better. And it's been getting better and oh, I'm a complete optimist so there would be no way that I could even make my mind think that he wouldn't get better... I can't wait until he's cured.

> (My husband thinks) all this stuff (interventions) is going to make him come out of it. I don't think he's realistic but I don't try to discourage it because he gets too upset.

In most families the hope for a cure was identified as such and not as a certainty. Parents of children who were non-verbal and showed few signs of progress were more guarded about the future.

> I think there might even be a chance he'd come out of it at some time. I know it's kind of rare but...I'll keep my hopes up for him. As long as he keeps on improving, I'll keep thinking that.
>
> I hope like about a couple years, he just comes up and says, 'Hey, Dad. I'm better now.' Simple as that...
>
> I think inevitably it's going to come. And I hope it may be in my lifetime that we find out what causes autism, what is the mechanism. But if it doesn't happen, I hope it happens in his lifetime. And if it doesn't happen in his lifetime, well, it will happen. I don't think humanity is going to have to suffer this particular kind of misery too much longer.

A great deal of uncertainty comes from not knowing or being able to predict the trajectory of autism in a particular child, therefore making it difficult to anticipate the future of the child, the future of the parent, or the future of the family. This unknown trajectory is the nature of the condition and while there is a general understanding that some aspects of autism improve with age and development there are no clear ways to predict what these will be for any given child. This aspect of autism perhaps more than any of the other concerns about the future was a profound source of stress for parents and children.

> What does life hold in store for someone like him. Is it going to be a group home? Is it going to be an asylum? Is it going to be a firing squad? I mean, who knows? How will he function without us? Or without

> someone? Or if so, who?
>
> I never know when everything's going to just fall apart underneath him. I never know... I think about sometimes at night when he's sleeping, will he ever wake up in the morning or will he just die? And would he be better off if he was... you know (if he did die).
>
> (At a social gathering for parents and persons with autism) I saw adults there that were wearing helmets and couldn't talk and damaging themselves, and banging their heads, and jumping around and that scared me. And then there was also a lady there, a teenager that held (my daughter) and that was able to relate perfectly well to her... And I just.. Is this going to happen to him 15 years down the road? Is he always going to (need) be taken to the bathroom? Is he never going to be able to talk?

Social and cultural concern. Concern for the child's welfare after parents were no longer living was a universal concern expressed by family members. At 11 years of age a sibling was very clear about his concern.

> The only thing I worry about is having to take care of him. When I grow up, and when my parents die who's going to take care of him?

Parents were also concerned about the availability of community resources for persons with autism and the negative view of persons with disabilities that predominates in a culture that highly values beauty, competency, individualism, and sameness. The following excerpt gives a glimpse of the folklore of being a parent of an autistic child. It conveys the hope for necessary community resources at the point in time that the child will need them much in the same way that parents of children without disabilities hope their children get into the right college, meet the right marriage partner, or get the best job.

> (All mothers of children with autism), when we first started out, if our kid would just talk. Oh, please God, if our kid could just talk. And he talked. If he could just say "Mama"...so that I knew that he could associate me with "mama." And I got "mama." Then it goes, Oh, God please have it where (my son) walks in the door and says, 'I'm going to play with somebody.' Oh, please God if you're going to give me something, give me something like a friend for (him). The next step is, Please God, make sure there's residential housing.

Planning for Care in the Future

The degree and depth of planning for the future without parents varied among families. In some families planning for the future did not go beyond hoping for as normal an adulthood as possible for the child.

> I take things day by day and whatever may happen 10, 15 years down the road, I can't...I really don't want to face the future because it's just like you don't know what's going to happen.

Older siblings were an integral part of planning for the future of the child with autism for some parents.

> I just try to make him the best person, and do the best I can. I don't think about the future that much. I mean, you do. We've made a will, so that my daughter takes care of the money but she's... I don't want her completely taking care of him, but I do want her watching him. So, we've set it up that she would take care of him and make sure that his hair is combed and people aren't abusing him. Look in on him and see how things are going, making sure that he has clean clothes, that no on's hurting him or stealing from him or anything. And that he has a TV if he needs it or a radio or whatever.

Institutionalization was not considered a viable option by most parents for their child with autism any more than it would have been considered a viable option for a child without autism. Parents were adamant about not placing their children in institutions and even group homes were suspect. Only two parents could even consider the possibility and institutionalization was viewed as an absolute last resort.

> I do not intend to institutionalize him at any point unless it's just beyond our capabilities. He would have to be to the point where we absolutely could not deal with him. And at this point, he's improved so much I don't foresee that. It may be a different story when he's 6 feet tall and weighs 200 pounds.
>
> Seeing Rain Man (a recent motion picture about an adult man affected by autism) didn't give me a lot of promise (about the future). He was in an institution and they took him out and they put him back. He (Rain Man) was put in at 5 years old, where (my son) is still in a house (at 5 years of age) where he's loved and going through school.

It was not an uncommon experience for parents to receive advice from health care professionals, family members, and friends place the child with autism in an institution. Such advice was deeply hurtful to parents and was interpreted as if they should discard their child because he was not perfect. It is difficult to convey the depth of commitment, love, responsibility, and caring that parents expressed for their autistic child. Once the depth of parental commitment was understood, it is not difficult to comprehend parental reluctance about institutionalization of a child with autism.

> (What worries me most about my son) is when I'm gone. I could live with him...I could even be poor, alone and live with him. I could manage to live with him. It's just that if I'm not there, the thought of what is...it's unbearable because he has no way of...Even in a group home, there's a victim. They're so vulnerable. It doesn't matter how cute he is or how easy he is to

> love or anything else. That's just the way the world is.
>
> But I think that it's just the idea that this is your child. You're the one who gave birth to this child...Even though I don't think that I caused it, I'm the one who brought him into the world...
>
> ...the only way you can cut the loss with the child is to send him to the institution and that's not acceptable. He is our child. Philosophically, we don't throw things away. We got into it, okay, we got handed a real curve ball on this one but it's my curve ball, and we cope and deal as best we can.
>
> ...I think that after I'm gone there won't be hardly anybody in the world that's going to love him the way his parents love him.

This is not to say that all parents wanted to be in the position of caring for their child with autism for all of the child's life. While all but one parent willingly considered the possibility of life-time care, other parents wanted to care for their child only as long as that was beneficial to the child and to a lesser extent, themselves. Two parents looked forward to the day that their autistic child would be living outside of the home so that parents could also have the time to do things considered important in their lives.

> As far as I'm concerned (he could live with us forever), but I'm not convinced that would necessarily be the best for him. And after a certain point, he's got to learn to take care of himself...
>
> I just don't want him home forever, (and it's not) because I don't love him and I don't think he deserves to be home. My husband would like to see him home forever. I don't. I want him to work in the community. Because if anything happens to us, he's going to be lost. He's got to be able to deal with life...And I want to be able to take a vacation and not worry about him.

Caring Today for the Future

All parents expressed concerns about the future and were involved in care with an eye toward the future. Planning for the future was not unique to the parents in this study. Many parents plan and care for the future of their child by encouraging them to stay in school, helping them plan for future job or college plans, and helping the child identify their strengths. However, the quality of planning and caring is different in families of children with autism. Study families were concerned about who would love and comfort their child, who would protect their child from the predators in our society, and who would teach him about the things he needed to know in the future, concerns that for parents of "normal" children become the child's to take on as she or he reaches adulthood.

Caring for the future took three general forms: family care, interventions for autism, and advocacy. A good family environment was viewed by all families as essential and basic to the overall growth and development for all of their children. Interventions described above were the family's investment in the future; through these interventions they could put their child with autism in the best possible place for treatments, scientific discoveries, or cures yet to come. Two parents had become very vocal advocates for their child as well as all children with autism. During an interview with one of these parents, he drew up the plans for an autism clinic he dreams of having in place some day.

The Meaning of Autism Symptoms

Kleinman (1988) states that symptoms of an illness are not objective, decontextualized "things." Rather, the interpretation and meaning of symptoms relies on shared understandings of those symptoms in the culture and different social groups. The symptoms of autism hold different meanings depending on whether one is a member of the lay public, a health care professional, or a parent. Families experience distress when the incongruous meaning worlds of parent-lay public, and parent-health care professionals clash. To better understand the distress, it is important to understand the different meaning worlds associated with the symptoms of autism.

Autism as misbehavior. To members of the general public the symptoms of autism are most often interpreted as evidence of either undisciplined children or ineffective parents. Children with autism have no visible stigmata, rather they appear quite normal, if not exceptionally attractive. Our cultural understanding of "normal" appearing children between the ages of 5 and 11 years of age who are hyperactive, pull hair, bite, pinch, play with the vegetable scales in grocery stores, run around loose in the store, scream inappropriately, have public tantrums, kick gravel while waiting in line at Disneyland, or grab and throw food in restaurants is that these children are misbehaving and that their parents ought to exert better control over their child's behavior.

> (In the grocery store) If he does a lot of screaming, things get bad. A lot of people come over and want to know why I'm such a bad mother...
>
> (In a restaurant) He spilled just about everything. He reaches out to get something to drink, you try to keep it away from him, and he tips it over before he gets it to his mouth. Reaches his hand in and spills it. He did it with my iced tea, he did it with his water, he did it with his milk. He grabs his food and lots of it goes on the floor, lots of it goes on his mouth, lots of it makes messies on the table. He doesn't only grab his food, your plate's better than his. So, he's always grabbing at your stuff, which makes it very very hard to eat, and you're always afraid that if you put your fork down, you'll end up putting it in his hand...you always wonder if people are watching you, and there were people watching us, I can feel it.

Care in public. Parents and families used a number of strategies for minimizing the distress (their own or that of others) associated with their child's "misbehavior" in public. The most common strategy used by parents was to attempt to educate those they encountered by interpreting their child's behavior as the signs and symptoms of autism. Parents would verbally tell someone they encountered that their child was autistic or they would offer a small printed card that provided a brief explanation of autism. One mother would go beyond the basic explanation and show people how to diminish her child's distress.

> If (my child) starts throwing a tantrum in a store, like if we're at a certain check stand...people will try to talk to him (to comfort him) and they'll say, "Oh, you don't talk to strangers." And he'll scream or

> sometimes he'll pinch one of us and I'll say, "Well, he's autistic." And I'll explain to them what upset him...it's that they've (the checker) put the ice cream on top of the ice cream cones or just some little thing. And I'll rearrange it and they'll see me do it and see him stop crying, and it gets people's interest. And I think well, maybe they'll think about it the next time they hear it (about autism) and they'll think, I've met somebody like that or I've seen them.

An alternative strategy used by parents was to normalize the behavior and then respond as they might with any other child. The particular strategy might vary from family to family but it was consistent with overall parental views about discipline. In one family this meant ignoring the child's behavior given the parent's perception that "it isn't any worse than some other 5 year old behavior I see in the store," as well as ignoring, or attempting to ignore, the response of others encountered. At times it was necessary to enlist the aid of the employees serving the public to help cope with the situation. Direct intervention with the child using traditional disciplinary strategies such as a stern voice, removal from the scene, or spanking was also used.

> He's all over the floor, making silly noises, doing interesting things, licking the table...You sort of have to corral him and...try to get him back in line. And I'm thinking, "What are other people thinking? You're sitting here with this kid...a 9 year old that's a twit." You just have to try to ignore it (other people). I try to ignore it and go on (with the discipline).

Intolerance for public insensitivity was of concern to a number of parents. However, only one parent had developed a confrontive style of dealing with what he perceived to be other's insensitivity (staring or verbal comments) to his son's autistic behavior. This father was tired of the work it took to engage in an ongoing dialogue with others about his child's socially inappropriate behavior.

> We were at the (grocery store) and (my son) pulled out his little penis and was stroking it to get hard. And I'm saying, "don't do that," and slapping his hand. Turned around because I was trying to (respond to the butcher who was handing me my purchase), and this lady came up to me and just glared at me. I sort of snapped and I said, "Don't worry lady, he's a communist. They have no morals." I got tired of having to explain to adults...I believe if you don't understand or you're ignorant of a certain situation (such as autism), it's your fault. Ignorance of life is no excuse.

<u>Autism as Hopeless Symptoms</u>. All of the study families had experienced a confusing diagnostic period related to the failure of health care professionals to recognize the signs and symptoms of autism. In all but two of the study families, health care professionals diagnosed initial parental concerns regarding the child's development as parenting problems, or as development that was within the range of normal. In the remaining families, one was able to justify the child's differentness to themselves and only at the age of 3 years pursued a professional opinion, and in the other, there was strong evidence to suggest that the pediatrician had monitored the child closely for a year prior to communicating a diagnosis and initiating referrals.

> Once you get the diagnosis, you can't get past the diagnosis, because then it becomes a case of, 'Well, I (health care professional) can't do anything about it.'

In contrast to the general public who fail to see the autism and see only the misbehavior of a child are the health care professionals who failed to see the child within the autism symptoms and/or failed to recognize the family's distress. A mother in the study described her child's diagnostic visit with a child psychologist as "devastating."

> (The diagnostician told us) Not to do anything with him. "It would not help. He's just going to be the way he is. When he gets older, he'll bury himself in his room and then maybe if you're real lucky you can put him in a half-way house." There's nothing you can do for him. He will always be this way.

This is a paradigm case of treating the child as an object and it is the parent's perspective, and perhaps not that of the health care professional's. However, it is clear that from the parents' perspective the clinician saw only the autism. The symptoms and the child were hopeless. There was no expressed professional concern for the child as a person or the meaning of the child or the diagnosis for the family. Fortunately, none of the other parents in the study had a diagnostic experience as personally devastating as this one. However, from the parents' perspective, health care professionals were of limited value in helping families identify resources, sort out treatment options, or address other family concerns once the diagnosis had been made. Referral to early intervention or the autism parent support group were often the extent of recommendations at the time of diagnosis.

> People who work with autistic children and see autistic children, they'll tell you that (speech therapy and sensory integration are important treatments in

> autism). And so, this research and that research, it's not very well documented and (physician) is only looking at strict proof. So, when I mentioned to him what we were doing he just completely poo-pooed it and made it sound like I was wasting my money. And there was no way that I could explain to him to what lengths I had gone before I made any decisions about what to do. There was no way to explain it to him, or how far out on a limb I had put the family budget, or what I did to who to get this or that. He had no way of knowing that, but still to just be dismissed out of hand. Now, that's when I felt angry with him.
>
> And the basic answer he (pediatrician) gave us when (my son) was diagnosed was, "you're the child's mother. Just be his mother and let the school take care of educating him. And just put him in a special program." And how can I just be the child's mother? I mean a mother's job is to educate their child. You teach your children things. You take your preschooler out for a walk and show them the trees and the flowers and talk about them.

Managing the "care" of professionals. Parents who found the recommendations of health care professionals wanting (all but one parent in this study) in some respect developed various strategies to deal with the limitations, such as those described above related to autism as a disease process. Parents initially worked hard to bridge the meaning gap but the all too often difficulty and futileness of negotiating a shared understanding between parent and professional is highlighted in the following excerpt:

> We've been taught from a young age to be respectful and intimidated by doctors. I can fight with a teacher. It's real hard for me to fight with a doctor. The usual pattern you end up adopting is you simply just go away, and you never go back to that doctor. But that doesn't get your child anything.

In this instance the mother wanted to pursue allergy testing as a possible contributor to her son's autism. The pediatrician had never heard of "brain allergies" and refused to do further testing because this child did not display rashes, respiratory problems or other signs of allergies. The pediatrician only saw the lack of legitimacy to further testing, he failed to see the parental distress and the potential impact of his refusal on her. Kleinman (1988) offers some insight as to why this communication breakdown takes place.

> The upshot is that practitioners, trained to think of "real" disease entities, with natural histories and precise outcomes, find chronic illness messy and threatening. They have been taught to regard with suspicion patients' illness narratives and causal beliefs. The form of those narratives and explanations may indicate a morbid process; the content may lead them astray (p. 17).

Cultural Significance of Autism

Finally, explanatory models of autism and the meanings of symptoms take place within a larger context of the cultural understanding or lack of understanding about autism. Early theoretical notions of autism put forth the idea that autism affected the children of highly intelligent, upper-class parents who were emotionally distant from their children. Scientific inquiry has not produced evidence to support this hypothesis. However, the knowledge and actions of some professionals described by parents in this study, suggest that portions of this psychogenic theory are not dead.

> I went to a conference on pregnancy loss and grieving, and they had this doctor from England come that was supposed to be the forerunner of all of this pregnancy

> loss business. And his theory was that autism was caused by mothers who had had a previous pregnancy loss that was unresolved.
>
> The (diagnostic center) basically told me that (my son's) problems were my fault. Their idea of therapy was to give me therapy. Not that I couldn't use it, but they were not going to work with (him). They were going to work with me.

Among the general public there appears to be little, if any understanding, of autism. The motion picture Rain Man was identified by parents as helpful in that at least some people had heard of autism. However, if the public's understanding was based on Rain Man, knowledge was limited to a particular expression of autism, the savant, and only one of the children in this study could be considered savant. For some parents, though, the movie provided a point of departure from which to discuss their child's autism.

Summary

Analysis of the data revealed important meaning systems within which families, the general public, and health care professionals operate. Within families, four explanatory accounts of autism were identified and their influence on decision-making, choice of treatment strategies, interpretation of the child's everyday behavior and progress, and individual approaches to dealing with the child were explored. The uncertainty and unpredictability of the future, the hopes for a child "making it", planning for care, and investing in the care of a child today for optimal functioning in the future, significant aspects of the family story, were elicited. Finally, the social and cultural meanings of autism among the lay public and health care professionals have been described.

Kleinman (1988) suggests several things about illness meanings. First, meanings are not static but rather evolve over time as a response to changes in the situation, relationships, and the overall trajectory of illness and life course. The explanatory accounts described are not mutually exclusive categories and are not intended to convey such, nor can any predictions be made about how they might change over time. Second, meanings are constituted within relationships as in this study was evidenced by the meanings uncovered between the interface of the child with family members, health care providers, and the general public. There is no judgment about the "rightness or wrongness" of the meanings of autism held by these different groups, for each in their own way may have been acting on behalf of what they believed to be the child's best interests.

Kleinman (1988) further suggests that the meanings communicated by illness can exacerbate or ameliorate symptoms, impede or facilitate treatment, emphasize or deemphasized disability, and that powerful emotions and interests become attached to illness meanings. In this study, evidence of the emotions associated with illness meanings was most apparent when the meaning system of the parent was confronted by that of the general public or health care providers who were not knowledgeable or sympathetic regarding the child with autism.

The implications for nursing of addressing illness meanings is speculative at this point, as this study was not designed to explore the effectiveness of including the elicitation of illness meanings as a nursing intervention. However, Kleinman (1988) has suggested that such an intervention has potential for diminishing the experienced distress of chronically ill persons and their families, enhancing the effectiveness of care, and diminishing the effects of disability. Nursing has a long tradition of attending to the practical as well as human aspects of health and illness, a tradition consistent with the understanding of illness meanings as an important caring practice.

Gadow (1989), a nurse philosopher, describes caring as the enhancement of the patient's or family's subjective or personal experience of a phenomenon. Within this view, advocacy is a moral position that involves assisting a person or family to reach decisions consistent with their own values, not necessarily the values of the clinician. This view of caring further supports Kleinman's suggestion that the negotiation of meaning systems is an integral part of sensitive and effective care. Further investigation is needed in order to understand in what way illness accounts are an important aspect of nursing care.

CHAPTER V

Care Demands and Concerns

Understanding the explanatory accounts of autism was an important aspect of understanding the central concerns of parents with respect to identification and pursuit of treatment strategies, and the interpretation of every day behavior. In this chapter the care demands created by the child's every day behavior will be explored in more depth and the caring practices generated by the concern of family members described.

Care demands of living with a child with autism refer to the contextual and situational aspects of living that require attention. The word concern describes how individuals and families involve themselves in these situations. For families in this study, shared demands and concerns arose from three sources: the autistic child's way of being in the world; the responses of individual family members to living with a child affected by autism; and the unending search for appropriate interventions and community resources. This chapter is presented in three sections: (a) the care demands and concerns that arise from the expression of autism in the child; (b) the individual family members' meanings of living with a child affected by autism; and (c) the individual ways family members involved themselves with care.

A Parent in Every Sense of the Word

From a medical or disease perspective such as that represented in the Diagnostic & Statistical Manual of Mental Disorders III-Revised (American Psychiatric Association, 1987), to say that a child has autism means that the child in question has difficulty interacting with the world in several ways. If the child has language he or she may speak without inflection, reverse pronouns, be echolalic, have limited capacity to put a number of words together or initiate conversation. The child may have limited tolerance for close physical human contact, or may not interact with parents, siblings or peers in an age-expected manner. Finally, the child may have a limited repertoire of activities and interests which means he or she may engage in self-stimulatory, self-injurious, ritualistic or obsessive behaviors. The severity and qualitative expression of each of these disturbances in function varies considerably across children diagnosed with autism.

From an illness perspective, parenting a child with autism means "being a parent in every sense of the word." Symptoms associated with autism are expressed in a variety of ways in family life. In order to understand the complexity of care required and the way families engage in care, it is important to understand the meaning of autism in everyday lived experience.

"They just can't communicate the way you and I do".

Because most children with autism do not communicate their thoughts, emotions, needs and desires in the usual way, family members were forced to learn new ways of interpreting and intervening with the child's behavior. As with any child, developing the ability to communicate was evolutionary in nature and all but one child with autism in this study was either currently pre-verbal, or had been pre-verbal in the past. The lack of expressive verbal language did not mean that the child was non-communicative or that family members were unable to respond to their needs, although for some children and families this was the case. Children who had developed expressive language were not without communication barriers and the demands and concerns in these families were qualitatively different from other families in the study.

For those children with autism who were without expressive language, the communication barriers permeated all aspects of daily life including the child's ability to communicate the need or desire for food, drink, toileting, recreation, or exploring the world. The principal demand created for family members was the inability to interpret the child's needs. The resulting frustration for child and parent is illustrated in this exemplar:

> The difficulty in communicating. It makes him frustrated because he cannot tell me what he wants. And I have to figure it out and it makes me frustrated because you can't always tell.

The interview narratives often touched on the difficulty family members had communicating with the child with autism but it was during family observation that the intensity of the work became most evident.

> (On a hot summer's day in the backyard) (Child) pulls at his father's hand and makes urgent sounding noises. Dad looks at his son with concern and repeatedly says "What?" He picks up his son's blanket, and gently moves a corner along his cheek. (Father) frowns and looks distressed as (child) continues to make even more urgent sounding vocalizations. Father then begins to gently scratch (his son's) legs and his torso. This also does not seem to do the trick as (child) continues his sounds. Next Dad puts (his son) on his shoulders, takes him over to the back fence and child peeks over the edge. He quiets. As long as Dad can hold him up to the fence (child) is content to look over. Three times Dad puts his son down thinking he is satisfied, only to have his son pull on his hand and take him to the fence. What he sees or experiences is a mystery to his father.

Two children were without expressive language but family members and child had worked out a number of communication strategies such as the child taking a parent's hand and leading him or her to what he wanted, making throat noises or primitive vocalizations, or, with the aid of some other physical object, demonstrating what he wanted. The demand to interpret the child's needs and desires had diminished in these families.

> It was like you were supposed to read his mind or he'd have a fit. Now he's more inclined to in some way or another find a way to communicate. And you're constantly looking for ways to improve the communication.

Even when everyday communication was fairly smooth functioning, a new situation, such as the child being injured, recreated the demand of not knowing how to interpret what was happening with the child. Not all family members had equal ability to understand and communicate with the child. In the following excerpt the sibling of an autistic child talks about the discrepancies in her own ability to interpret her brother's communication and that of her mother's ability to interpret her son.

> Now the way he communicates with us is he takes our hand and he does something with it. Like when he, like this is the toughest one he's done so far, he gets my mom's hand and puts it on the steering wheel when we're about to go. And my mom doesn't know what that means. And my mom's trying to ask me what that means...it means hurry up and go. You see, he knows you need to have your hands on the steering wheel to go. But he doesn't understand the gas peddle. I can understand all the other ones, they're real simple. Like sometimes he takes my hand and sticks it on a door (which means he wants you to open the door).

At the time of the study two of the children with autism were verbal; one of these children had essentially no difficulty with language while the other was bothered by some pronomial reversal, echolalia, flat affect, and at times unclear pronunciation. One of the day-to-day stressors for the father in this family was his son's language difficulties.

> ...see how he get's his "me" and "you" and this and that mixed up? I get stressed, not stressed, but I get a little peeved at him because of that...

Responding to a child's needs, desires, and distress is central to being a parent. For the parent of an infant who is non-verbal (but not uncommunicative) the possible sources of distress or desires for pleasure are fairly limited and well understood by most parents given practice and experience. As a child grows older and his needs become more complex family members rely more and more on their child's ability to verbally communicate his needs.

Learning to communicate. Learning to interpret the child's needs was accomplished for the most part by spending time with the child, trial and error, learning his habits, and carefully watching his responses in different situations. The central concern of the parent was to understand and respond, a practice taken for granted by many parents of non-disabled children.

> I just watched him a lot, and I (saw) what it was he was doing before he got to the tantrum point. I'd start hearing the different throat noises and I'd get in and I'd start interacting with him and say, "Show me (son), show me." And he'd take my hands and he showed me there's a little edge here. And I'd put my fingers on it (cheese hanging over the side of the cheeseburger) and I'd tear it off. And he'd look at me and smile and then he'd push my hand away. Saying, you know, it's done, and then he'd eat.

All but one of the children with autism in this study had gone through a period of time when they were non-verbal and parents had used a variety of strategies to address the concern that their autistic child learn to communicate. Family members' efforts to teach communication to their children were facilitated by the fact that most children with autism have better receptive language than expressive language (Schreibman, 1988). Some families introduced pictures of family members, school teachers, dry cleaners, fast food restaurants, and food when trying to determine what their child wanted. In another family, flash cards and sign language were used to teach the concept of language and he learned to read prior to the time he learned to speak. A stack of flash cards tied to his belt allowed this child to communicate his needs.

> And then he had huge amounts (of words on his belt) so he would just flip through those things like mad. He could tell you anything he wanted through the belt.

Several mothers integrated teaching and play:

> I remember one of the happiest times was when he first started talking. We'd worked on this one toy that he got, he just loved it. It was a pop-up toy that made the animal sounds. There was a dog, a cat, a chicken, and a rabbit. We'd sit there and we'd go over and over it again. And most people thought it was monotonous. It would kind of get on their nerves. Dog, ruff ruff. Cat, meow. Chicken, cluck cluck. Rabbit and then we'd push it and make it go hop hop hop. And we'd go over it and over it and he'd do it over and over again. And he wouldn't play with it by himself, I always had to be there. And after every one, he'd touch my mouth and he'd want me to say what it was and what type of a sound it made. And we did that for about 3 or 4 months. One day I went in and he sat on my lap and I pushed the button and waited for him to touch my mouth, and he goes, "Dog, ruff ruff." And I just looked at him and I did the next one, and he goes, "Cat, meow, meow." And they were all in whispers. I said, "Good, good." And he started clapping for himself and he did the next one and then I started crying. And he sat there and then he wanted off my lap and he sat on the floor and he started saying them a little bit louder and a little bit louder. It was really neat.

The children with autism in this study had a wide range of ability and disability in communicating and the use of visual and tactile learning activities were successful teaching strategies in facilitating communication. For some families teaching communication strategies to their child was a high priority, while in others, even when the child was without expressive language and mostly noncommunicative, very little family energy was invested in these teaching-learning activities. There were no consistent similarities in explanatory accounts that might help explain this difference; however, the available energy in the family to take on teaching seemed limited in those where there were no ongoing in-home teaching activities.

"He just does whatever gets into his head whenever he gets it into his head"

The demand exemplified in this parent's comment is complex and encompasses a number of aspects of autism including the inability of the child to make qualitative distinctions and communicate his needs. Whatever the underlying reasons for the behaviors, they presented family members with a day-to-day family life in which very little could be taken for granted.

> Then I try to keep him occupied while I take my shower and get dressed. I get a tape or something he likes to watch and lock the family room door and hope he doesn't get into anything. And quickly take my shower and get my clothes on and I come out here and see what he's gotten into. And half the time he's gotten into something he's not supposed to, so I have to clean up whatever he destroyed.

All family members experienced bewilderment, frustration, fear, anger, and fatigue as a result of the unpredictable and at times intractable behaviors engaged in by children with autism. Climbing on kitchen counters, ladders, and out of windows regardless of their height; running away or leaving a parent without asking permission;

unsupervised use of the microwave oven; setting fires; running into the street; relentless insistence on going to the store for a treat; grabbing food from another family members's plate; rummaging through the refrigerator or cupboards; playing in the middle of the night; wanting to go outside, for a ride, or visit a relative's house numerous times a day; removing windows from their casements; unrolling and "playing" in a bundle of home insulation; and "hounding" a parent until the child got his way are examples of the types of behaviors engaged in by the children with autism in this study.

Depending on the concern generated by the behavior, parents and siblings had developed a number of strategies to manage the autistic child, the environment or their responses in the situation. Sometimes, the solution to a problem was as simple as unplugging the microwave oven when not in use. In three families the child's climbing proclivities seemed to go unnoticed and limit setting around this behavior was minimal--if not nonexistent--while in a fourth family more traditional forms of discipline such as yelling and spanking were used in attempts to extinguish this behavior.

More often when the concern for safety or protecting the autistic child from danger was ongoing, a vigilant stance had become a way of being in the world for many parents. For some parents the need to be "always on" had become the primary meaning of having an autistic child.

> There's a lot of stress and anxiety involved to make sure that he doesn't injure himself. Front door is left open, he runs out in the street. He doesn't have any fear. He doesn't understand that cars might run over him. Climbing. He's a real climber. He stands on window sills. Just constant surveillance. I think that's a good word for it. I have to be constantly alert to see what he might get into that he might injure himself. Also, if we go anywhere to make sure he doesn't totally destroy wherever we've gone.

> I get so distracted because...it tends to be one thing after another, after another, after another that I have to jump on...I have to physically drop everything and go and (intervene with him)...

> He doesn't have this self-protective, the ability to protect himself, and so, he has to be constantly protected. He did that today. We took him to the train station, and he runs right out of the station right out into the middle of the street.

> I don't worry as much like about people picking him up and things like that because I'm always with him.

Aids to parental vigilance in those families concerned with safety came in the form of locks or buzzers on outside doors and fenced yards. For a period of time two mothers had resorted to using a child harness, a device both had disdained prior to their experiences with an autistic child.

Making rules about potentially dangerous behavior was an effective strategy in two families. Based on the recommendation of an autism consultant the "running off" behavior of one child was improved considerably.

> He was running off from me. He would see something and he'd leave and he wouldn't say where he was going...he'd just take off. But then (the autism consultant) put a thing together. And Rule #12 is "(Child's name) will ask permission when he leaves

> Mom." And he carries this card on him now, or I do. And if I go to the store we talk over the card. We go to the store, I have him hold it (the card) or put it in his pocket. And I try to catch him before he darts off now, and I'll go, "Rule #12..." and then he goes "(Child's name) has to ask permission..." So, it's just another rule that he has to live by.

Some of the behaviors described above were not dangerous but were considered intrusive by family members in one way or another. Strategies used to address these demands were more individualized and tended to attempt striking a balance between what the child with autism needed and what the rest of the family needed. These strategies often became a regular part of everyday life. For example, sleeping for the entire family was facilitated by locking the child in his room at night (in one family for the entire night, in another family just until the child went to sleep), allowing the child to sleep with one of the parents or the parent to sleep with the child. In three families the autistic child's irregular sleeping patterns resulted in parents not sharing the same bed for part or all of the night over extended periods of time. Mealtimes in another family included guarding one's plate from the autistic child who when finished with his plate, would grab for the food of others.

A common characteristic among three of the children with autism in this study was their desire to be "on the go". Whether the child liked to go places outside the home, go for walks, go to the store, or just be outside, "going" was at times a family demand.

> And where he still wants to go over there (to relative's house) 3 and 4 times a day, sometimes he'll go in and he'll walk straight through the house and out the back door and right back to the car and jump in, and he (doesn't) want to stay. And other times I can't make him leave. And that's when his tantrums start.

"<u>He apparently cannot establish meaning</u>..."

A consistent feature of the children with autism in this study was their difficulty in transferring one learning experience to another similar experience, discerning the appropriateness of behavior in one setting and not another, and understanding that one negative experience at one point in time does not mean experiencing the same negative experience the next time. This inability to make qualitative distinctions was perplexing and demanding for parents. The meaning of this characteristic is conveyed best through example.

> This is a classic. When he was younger we would ride around and each and every highway sign we would pass, he would recite it to me. Now, a year or so later (after he had started school) he would hide his eyes every time we would pass one of these highway signs. I says, "What is this? What's going on? Why are you doing that?" And he didn't say. I couldn't get out of him what the problem was so I finally gave up on it. And one day we were having a real good time, driving to the coast, and we're passing one of these highway signs again and he's hiding his eyes. I said, "What is that? Why do you do that every time we pass one of those?" He says, "No dots. No periods." And I looked at the sign and it says 35 MPH. It's supposed to say 35 M.P.H. He was not wanting to see a sign that was incorrect because he (had learned in school) that everything that's abbreviated has to have a dot after it, and he didn't want to see that they'd made a mistake.

In a separate incident this same child failed to understand the circumstances under which one calls 911 for help.

> When he gets in trouble he has like a panic attack. When he knows something is wrong and he'll go, "Call 911. Call the police." And he'll even try to call the police himself. He thinks that they save him from everything. (One time) I was mad at him and I said, "(Child's name) I don't like what you're doing." So, I was going to go downstairs and I just happened to turn around and there he was on the phone. And I heard him say something like, "Help! I need an ambulance. Come quick." And I went, "Oh my gosh!" I knew he'd called. I don't know why but I just knew it. I said, "Did you call 911?" And he didn't say anything so I called them and they did get the phone call. And I said, "Please don't send anybody out. He's autistic. You can come out and check on him if you want, but there's nothing wrong. It's just his way of asking for help." So I took all the phones out of the house. I mean I disconnected everything except the main phone until I could consult with (the parent of a child with autism who helps us with behavior management).

For one study family the autistic child's inability to understand that a mishap at one point in time does not mean a mishap every time he engages in the same activity has meant that his mother attempts to anticipate all that might go wrong before she introduces her son to an activity. She learned this early on when she was in a swimming pool with her son.

> ...when you have something that's frightened him, and it's real hard to scare him, but if you can do it, that is immediately lodged in his long-term memory. He will not come close to doing the same thing again, ever. My example for this is one time I had him swimming and was very carefully trying to get him to get into the pool. And got him into the pool and he was having a good time, gosh it was a big bathtub. And I made the mistake of dunking him because he was fighting having the water put on his face. That was the end of that. It took two people to pull him off of me, he was that scared. And from then on, I cannot get into the pool with him.

Slight changes in wording could provoke a tantrum in a child whose mother had worked very hard to understand her son's world in order to minimize his discomfort.

> He wants me to say, "to go see grandpa", and if I say "grandpa" he gets mad. He wants it to be "to go see grandpa." And little things like that I can't understand why it has to be that certain way but I think it's just because he needs that to really know that that's what he's going to do.

Specific sounds would often trigger one of the autistic children in the study to action. One evening during a home observation the sound of running bath water prompted this child to begin getting ready for his bath. The problem was that the bath water was for his brother. For the child with autism, the sound of running bath water meant it was time for him to take a bath.

> During an observation on a Friday evening. Mom and Dad seemed very tired. They had limited patience with the children who were physically and verbally active this evening. (One sibling) was reprimanded and spanked for jumping on his father's back. (Another sibling) was begrudgingly given a hug by his father after dad was reminded that he had promised at least one hug a day. (Child with autism) had wet his pants after being taken to the bathroom without results 3 times. In short, it was a hectic scene and both parents had limited reserves. (Younger sibling) for some reason went in and turned on the bath water, perhaps because he wanted to take a bath. The instant (child with autism) heard the water running he immediately began to frantically take off his clothes. His mother's attempts to tell him "no" were to no avail, and (child who had turned on the bath water) started crying when mom yelled for him to turn off the bath water. It was only after dad ran to the bathroom to turn off the water that (child with autism) stopped undressing.

Less involved yet just as dramatic examples of the disruption in making qualitative distinctions showed up consistently in the narratives. Parents from different study families reported instances such as the child with autism urinating in a display toilet in Sears, playing with fire and having only a small glass of water handy with which to extinguish it if needed, consuming potentially harmful substances, such as medications in the home and plants of unknown toxicity, and the inability to "read" the facial expressions of family members such as anger, joy, or tiredness.

These incidents had stimulated family members to learn the child's ways of responding and communicating so that they could effectively facilitate the situation. Living by the rules had become an effective management strategy in the family who used rules such as 'Rule # 12.' In family 1, the mother worked on an ongoing basis to understand her child's world in order to minimize the distress he experienced in various situations. In family 2, the key to the autistic child's seeming reflexive behavior to sound stimuli had yet to be found and the family was left to respond in whatever way possible when these incidents occurred.

"...he's just not a social being"

To some extent this parental quote may be misleading in that all of the children with autism whose families participated in the study were social in their unique ways. The demands created for parents in this area are related to the child's "inappropriate or eccentric" social way of being in the world. The demands created by the child's at times inappropriate public behavior have been addressed previously under the meaning of the symptoms of autism. Discussed here are the demands created by the autistic child's different ways of attending and responding to social cues and affection. Also embedded in these exemplars was further evidence of the autistic child's inability to make qualitative distinctions, communicate thoughts and emotions, and impulsive behavior. They are presented here because it is in the context of being social or relating to family members and others that they were most salient.

Perhaps one of the most often cited or well known characteristics of autism is the child's lack of relatedness with other people. Parents in this study reported that their affected children experienced what seemed to be a heightened sensitivity to close physical contact such as hugging, kissing, and cuddling. The child's response to such activities was to resist another person's attempts at close contact. Establishing eye contact with the autistic child was an ongoing concern and emphasis of care in five of the study families.

While most of the children with autism in this study had experienced or continued to experience some apparent dislike or withdrawal from displays of physical affection or both, for the most part these were not asocial children. Rather, in their own way and within the context of their family and familiar surroundings, they were loving and lovable responsive children as demonstrated in the following exemplars.

> I guess it's just that he's himself. It would really leave a big hole in our lives (if we didn't have him). He's really a peaceful guy to hang around with. One night I was saying, "Oh please God, fix this little baby. Please fix this little baby." He turned around (and) out of the corner of his eye he looked at me and he started to cry. And I thought "Ooh, I shouldn't ought to say that."
>
> (From a 5 year old autistic child who is essentially non-verbal, ritualistic, and destructive when tantrums) At the end of the day when he's happy and he tells me good night and he loves me and he kisses me on the cheek I think, "I'm so lucky to have such a cute little boy."
>
> When I'm feeling really down, it's real special to have him come and crawl up on my lap and give me a big hug and smile at me. And knowing that he knows I'm his mother, because I don't think he knew I was his mother before when we were at the worst point.

The definition of autism serves well as a representation for the medical and cultural understanding of autism: "an absorption in self-centered subjective activity especially when accompanied with marked withdrawal from reality" (Webster's Ninth New Collegiate Dictionary, 1988). Given such an understanding, these examples of relatedness may seem surprising and were often cited by parents as occasions that made them wonder if their child was really autistic. For the study families, social relatedness was not an all or nothing phenomenon. Given the information that had been given to them by professionals or what they had gleaned from reading, parents were often surprised at their autistic child's ability, although qualitatively different from their experience with children who did not have autism, to relate responsively and affectionately with family members.

Some of the most demanding situations for family members occurred when the child displayed private behaviors in public or engaged in behaviors considered to be socially unacceptable. Masturbation in public, feces smearing, and the child picking his nose and eating the contents are examples of embarrassing and inappropriate social behaviors cited as disturbing to parents. Even though the smearing of feces was a behavior that occurred within the home it was referred to as "probably the most embarrassing thing he did."

> This child was a feces smearer and if there was anything that was the antithesis of what I thought my child would be, that has got to be it. He'd smear himself. He'd smear his clothes. He'd smear the rug. He'd smear the walls. He'd smear the drapes. He'd smear the dog, the stairwell, the stairs, the toys, the bathtub.

Finding effective ways of managing this problem was very difficult. Parents tried physical punishment (which did not seem effective in extinguishing the behavior), time out (a more useful strategy), minimizing their response to the behavior, positive reinforcement, and initiating rules (an effective strategy for one child) to teach more appropriate child behaviors. Families received no help from health care professionals and relied on their theoretical knowledge of child discipline, information from other parents of autistic children, and practical knowledge of their child to help them know how best to manage these situations.

The autistic child's social relatedness with persons outside the home, such as playmates, teachers, and other adults varied widely among the study families, but social skills with others tended to be somewhat delayed or inappropriate. The diversity of social relatedness is captured in the following excerpts:

> He's always been pretty social in that he liked being around other people. Even though he was not able to interact, he liked being around; he didn't like being alone. And he loves being around other children, but he was unable to interact with them.

> (Regarding the morning family routine) Normally, if he sees that I'm out (in the kitchen) he'll go back in his room. He doesn't want to bother with anybody early in the morning...sometimes he does though and he'll come out and doesn't say anything. I've got to remind him to say good morning. And he doesn't like to talk to anybody he doesn't know or play with the other kids.

One of the study children affected by autism played better with younger children and another, at the age of 6 years, had no playmates in the neighborhood but was beginning to develop relationships at school. Parents described very few instances of other children being cruel or insensitive to their autistic children. However, one sibling recounted negative comments made to her brother as well as to her by school children. Parental concerns about social skills were more salient among those who had children that were verbal, perhaps because these parents no longer needed to be quite so concerned about language development, a bench mark of overall functioning and future trajectory.

"Stimming"

All of the children with autism in this study had engaged in repetitive, self-stimulatory activities, often referred to by family members as "stimming." The following are examples of the types of stimming behaviors reported or observed in autistic children: repetitive head-banging on the floor; clapping for long periods of time; hand and arm flapping; ripping any kind of paper in the house including books, newspapers, mail, or pictures; yelling out; visual stimulation by lining up objects and moving back and forth in close proximity while gazing out the corner of the eye; and breaking light bulbs.

Care demands and concerns related to this type of activity were dependent on the meaning of the behavior for the family members. Stimming behaviors were interpreted as demanding when they were intrusive, destructive, or injurious in nature. At times family members experienced fatigue and irritation at the unrelenting, intractable nature of stimming.

> My husband, daughter, and I would get crazy with the clapping. He would clap sometimes, he'd go into his world for 4 or 5 hours at a time when he was younger. I mean, we yelled, we screamed, 'Don't do it.' We were trying to get him out of his world. All of us started arguing about it because it was just getting on our nerves so bad.

Parents initiated caring practices designed to protect, distract or teach the child alternative activities when behaviors were interpreted as injurious to the child.

> He'd be going into his clapping and I'd bring him out of it. I'd say, "Oh no, we haven't got time to clap right now." And then I'd throw him in the bathtub with a million toys and I would play and splash and throw balls, anything I could think of to do in the bathtub. Anything to bring him out of his world.
>
> When he bangs his head into the floor, I sit and hold his head in my lap so he won't hurt himself.
>
> I'm having a lot harder time just stopping him from physically hurting himself. And that's getting a little bit scary for me. Like he fell down the slide and he wanted to keep falling down the slide. He didn't want to get up and slide again. So, it's like I have to reteach things that he's already learned, like "you climb up and then you slide down." It's not "You walk up and fall." And it's always something new, that's really a challenge.

Destructive behaviors required vigilance to keep the child with autism away from those materials he found particularly stimulating, or to teach him different outlets for his destructive energies. Stimming activities that were not self-injurious, destructive, or intrusive in nature were viewed by most family members as part of who the child was and little or no effort was made to interrupt or extinguish these behaviors.

With one exception stimming was not identified in the narratives as a stressful aspect of living with an autistic child. It was during observations that the investigator became aware of stimming and the practices that family members had developed in managing these behaviors.

"Things have to be just so, or he won't have anything to do with it."

Numerous examples of the autistic child's reliance on or desire for sameness were evident in the narratives as well as during observations. Examples of this type of behavior included the following: visitors must remove their shoes when entering the house; the television must be on a particular channel even though the child does not watch the television; clothing must be changed if even the smallest amount of dirt is present on them; food cannot be touching on the plate or food must be presented on the same plate for each meal or the child will not eat; the child will eat only certain foods; furniture or objects on bookshelves or tables must not be rearranged or confusion or tantrums are the result.

Once the parent had learned of these ritualistic behaviors, they were for the most part tolerated and attended to. If the parent had not yet been able to decipher the source of the child's distress around these issues then it became a demanding situation.

Breakthroughs

Children with autism presented unique care demands to family members thereby increasing the complexity of caring and one was a parent in every sense of the word. Caring takes place within a relationship, and for purposes of this discussion, within the parent-child relationship. Noddings

(1984) suggests that reciprocity is an important aspect in developing and sustaining a caring relationship. Although the parents set the tone and attitude of the caring relationship, children participated in sustaining the care by responding to the caring efforts of the parent (Noddings, 1984). How do family members, and parents in particular, maintain a caring relationship with a child whose way of being in the world is so different from what we expect in children?

It is not the intent to discuss caring as if it were a series of checks and balances but the rewards of parenting a child without communication disabilities are so taken for granted that in the case of autism they become glaring in their absence. Parents expect to be able to see the results of their care: the distressed child who quiets when held, the unruly child who eventually responds to effective discipline, the confused child who responds to a parent's explanation, the frightened child whose tense face relaxes with reassurance, and the happy child who shares her accomplishments with a parent. In each instance, the child responds to the particular form of the parental concern (being held, disciplined, taught, reassured) or initiates a sharing of her world with the parent. These instances of reciprocal caring may be so embedded in the everyday world of most parents that they go unnoticed.

The visible, responsive evidence of care that comes from the child with autism in some respects was no different than that observed in a child without autism. Parents of children with autism were sustained by behavior from their child that indicated the child responded to the form of parental concern, such as successful attempts to teach the child to communicate, the worry of a mother who asks God to "fix this little baby" and the child's responsive tears, or the child who climbs in his mother's lap and offers a hug at the end of a long day. What was different about these events was the fact that they did not occur everyday and were experienced by parents as breakthroughs being made with the affected child.

The determination of what constituted a breakthrough varied from child to child and from family member to family member. Breakthroughs were indicators of progress and were often established by the parents as a goal or benchmark of growth and development. In two families the hoped for indicator of progress was for the child to learn to talk while in another the goal was for the child to initiate and respond to gestures of love and affection. These goals or indicators of progress were achievable in nature and created possibilities for involvement in care in a situation where one could be easily overwhelmed.

As will be discussed in the section of this chapter related to individual caring practices, individual background meanings of parents also contributed as a source of sustaining care. For one parent, caring for her child with autism was a continuation of how she had always seen herself, caring for other children who were different. For a father, the rewards of caring were seen as evidence that he was providing something for his son that his own family had never provided for him, stability and not abandoning a child in trouble.

Seeing progress, or seeing one's child grow, develop and be happy, was not as obvious on a day to day basis as with children not affected by autism. Progress came in subtle ways and often after great energy expenditure of the family, but it did come for most families. In the following excerpt, a mother talks about her son now in contrast to a year ago.

> He doesn't talk. He does understand some now as long as it's simple commands, but back when he was first diagnosed I don't think he understood anything. He was literally to the point I would say almost as a wild animal. The only way he knew to express himself or get what he wanted was to grab and lunge and throw tantrums, and bite. And he didn't want to be held, and now he's much more cuddly, and he is learning alternate methods of communication...(it's) a very exciting experience that we are obviously making a difference for him...We don't care how much it costs, we're still going to do this. We're not going back to the way life was.

In families where progress was elusive or difficult to see families were despondent and discouraged about their child, themselves, and the whole situation. In the following quote, Noddings (1984) describes the central role of reciprocity in sustaining a caring involvement and the result of care always given and never responded to.

> What the cared-for (in this instance, the child with autism) gives to the relation either in direct response to the one-caring or in personal delight or in happy growth before her eyes is genuine reciprocity. It contributes to the maintenance of the relation and serves to prevent the caring from turning back on the one-caring in the form of anguish and concern for self. (p. 74)

Understanding breakthroughs and the importance of seeing progress as important factors in sustaining a caring involved parent-child connection have implications for nursing practice and research, particularly in those families where the child with autism has made little progress. A beginning point would be a consideration of the benchmark or indicator of progress held by the parent. First, is there a benchmark? If not, the nurse could facilitate the parent getting to "know" their child in a way that the parent could see possibilities for progress. If there is a benchmark, does it seem realistic, given the capabilities of the child as the nurse sees him? If not, smaller benchmarks related to the larger goal could be pointed out to the parent and in this way perhaps hope and involvement with care could be sustained. In some instances, the benchmark may need to be revised and the nurse could assist the family in identifying other meaningful strengths and indicators of progress.

"He's Not the Worst Part of It, You Know": Individual Meanings of Autism

This parent quote is used to capture the distinction between care demands that arise from the child with autism and those that arise from the individual and family response to living with a child with autism. The phrase is also used to emphasize that living with a child affected by autism is a potentially stressful situation, and that the source of stressors does not reside solely within the child with autism. These demands and concerns became evident when parents discussed the personal impact of having a child with autism, and when parents and siblings discussed the result of much necessary energy being devoted to one child in the family. The individual meanings of living with a child with autism are presented below.

Tearing and rebuilding of the dream: The personal impact on parents

Common themes related to the personal impact of having a child with autism included coping with the emotional impact of the diagnosis of autism in a child, rearranging expectations of themselves as parents, reconsidering personal goals and making work adjustments, and coping with fatigue and diminished opportunities for leisure.

Coping with the emotions of parenting a child with autism.

The emotional experience of learning that their child had a severe disability was intense and for many parents touched a core aspect of their being. Desolation, devastation, depression, anger, frustration, helplessness, embarrassment, and guilt were common emotions expressed by parents.

> I'm really depressed but there's a part of me inside (that) I'm stuffing down as hard as I can, that's hysterical. I can feel it in there, I can't squash it down far enough. It's really scary. Really scary. And I know I can't leave a person in this world that can't take care of themselves. Every (parent) of an autistic child knows it on some gut level and it really freaks them out.

For some, these emotions were complicated or intensified by a sense that even though their spouse and extended family were present and perhaps feeling equally devastated, they were not always able to talk about these feelings with one another, and a sense of aloneness was conveyed in many different aspects of family members' stories. The following exemplars, from parents whose children were diagnosed 5 years and 1 year respectively prior to this study illustrate the ongoing nature of existentially being alone throughout this experience.

> I have realized that nobody else is going to do for him. I'm the only one. My husband is of course there and working also, but he has to go out and work to bring the money so that we can survive. He doesn't see some of the stuff I see.
>
> IN: Where do you get your support? How do you deal with all of this?
> RE: I think I probably don't get it. I eat. That's what I do.
> IN: Does it seem like you're pretty alone in this?
> RE: You are alone. No one can help you. That's really what it is.

Fathers did not always speak explicitly about their emotional responses to having a child with autism. For some, the frustration with their perceived inability to take action to help their child in a meaningful way was expressed as anger, disappointment, and defeat.

> It's the helplessness of not being able to reach in there and pull out the idea (of what's going on inside his head), so we can't help.
>
> It's just that I'm angry that people don't provide even minimal support for these children and I'm angry that I have to be angry. I mean, that's another thing...part of the being on it all of the time is that you have to be angry a lot of the time.

The opportunity to participate in this study was experienced as therapeutic by some fathers who had never talked with anyone about their thoughts and feelings before. For other fathers the research experience was not therapeutic in that talking about experiences rekindled frustration and anger that had yet to find a release.

Upon diagnosis, many families had been referred by professionals to a support group for parents of children with autism. The support group has an educational format in that a "professional" from the community is invited to speak at the group's monthly meeting. At the meetings, parents also talk and make connections among themselves, exchanging phone numbers and resource information. Making these connections was considered extremely valuable to all parents but some found that sharing the depth of their emotions with other parents was not always a comfortable experience.

> ...a support group...For the most part, the parents of autistic children are not that way (emotionally

> supportive) with one another. You might get a flash of it occasionally. Like one day I went to (grocery store) and I saw another (mother) there and I looked at her and said, "This really hurts." And she said, "I know, it really does." And it was just one little sentence but it was like a huge thing to me. I remember when I was talking to (another mother) and I was crying at something and she just couldn't...for a couple of months I thought she was some kind of terrible ogre person. And actually, later on I looked at her and I could see right underneath there, she couldn't let me cry because it would just do her in. Right under the surface there. And it's a really horrible thing. You do not let it show, you do not let it out there. You can't really cry...

How are we to interpret this "inability" of one parent to share in the suffering of another? Hauerwas (1986) suggests that as humans we naturally avoid the expression of our suffering. Rather, we put on pleasant faces, smile at the world, and cover over our pain. Humans understand that by expressing their suffering they may actually distance themselves from those whose support they most need. Loneliness that arises out of suffering is feared as much as the suffering itself. Humans seek to deny their mutual reliance on others as much as possible for to need someone else somehow makes one vulnerable of not being the independent competent persons so highly valued in our culture. As Hauerwas (1986) states:

> That we avoid the sufferer is not because we are deeply unsympathetic or inhumane, but because of the very character of suffering. By its very nature suffering alienates us not only from one another but from ourselves, especially suffering which we undergo, which is not easily integrated into our ongoing projects or hopes. To suffer is to have our identity threatened physically, psychologically, and morally. Thus our suffering even makes us unsure of who we are.

In Hauerwas's terms, all parents in this study suffered, although their expressions of suffering were as diverse as the expression of autism in their children. A question that arises from this observation is, do nurses obscure suffering by using terms such as ineffective family coping or alteration in family processes as nursing diagnoses? If those who are suffering do so because the very essence of their being is threatened, how do nurses support them in their aloneness by labeling their responses ineffective or altered, based on an assessment revealing a family's lack of adaptation? The usage of language such as "ineffective" may distance nurses from the experience of the patient or family. If a nursing diagnosis provides a focus for nursing care, then perhaps a more sensitive diagnosis in this instance would be "suffering and distressing family coping." Nursing practice could then focus equally on bearing witness to the family's experience as well as offering specific interventions designed to facilitate healthy coping strategies.

Revising notions of being a parent. The diagnosis of autism or the gradual understanding of how the diagnosis of autism would affect the life of their child meant that parents were forced to learn new ways of being parents to their children, ways they had never anticipated prior to the experience.

> When we thought about having a child it was with the idea in mind that we would be guardians, teachers,

> exploration partners, mentors, all of that kind of stuff...And what have I had to be? I've had to be an advocate, a researcher...I can't even be a friend to (my son). On a very basic level you expect that at least you might once in awhile enjoy your child and enjoy the sheer wonder of exploration and discovery. And we've (had very little of that).
>
> I wanted for (my son) all the things that I had and then some. Since that dream is broken, I've had to develop other dreams.

Although mothers and fathers expressed similar thoughts, it was fathers who spoke most intensely and poignantly about the loss of the anticipated father-son relationship and their efforts to develop a meaningful relationship based on the capacity of their son to enjoy the world.

> Like up in the woods. For (my son) to go down and poke the edge of the lake with his stick and (make noises) out at the water and run back and forth and get to have cocoa. This is pretty much pleasing to him. He didn't really want to do what other kids would do, run around the lake, get up in the boat and go fish on the lake, go out and hike around, look for bears. He does not do that. So in a sense there's not a lot for him to do in places where many kids have a lot to do...We have no idea if he's enjoying himself or not.

Fathers had learned to take the cues from their sons about the things they enjoyed, such activities as hiking, walking, running through the sprinkler on a hot summer day, working on household projects together, going shopping, and just plain 'going'. The thrill of discovering an activity enjoyable to their sons is conveyed in the following exemplar.

> When we discover something that he likes, we get an extra kick out of it. As I mentioned, we were down in Mexico, and we took him to the ocean. He got him in

> there and just like his whole face lit up. So he went out and he just body surfed up a storm and had a gas. In fact he came back home and he had a suntan except for these little dimples (in his face) where he'd been grinning the whole time.

Leonard (1988) has pointed out how our culture views children as products or outcomes of invested parental energy. Evidence of this cultural view is found in the common everyday practice of sharing the accomplishments of our children with those around us at work. For fathers in this study, these casual discussions were further reminders that their child was different.

> So, yes, I am a parent like many other men and it gives me that in common. I don't have some of the same experiences that they do. They are saying (at work), "We went to a ball game and rooted for the team." And I say, "Well last night we worked very hard on trying to say "Move."

Revising personal and career goals. Being the parent of a child with autism demands time and energy. For those mothers and fathers with work and career goals outside of the home, the demanding nature of parenting often interfered or impacted work schedules or long-term career advancement. Putting work and career plans on hold was a shared experience for 5 of the 7 mothers in this study. Although being delayed in pursuing one's career opportunities was the most common experience, two mothers had discovered new possibilities derived from their experiences with their autistic children.

> I think having a child like (my son) has really pointed out to me where my strengths are. And it took me a long time to find out what they are, but I think having

> (my son) has really challenged me to the point that I...I think (what I've learned with him) can be translatable to a career goal.

Pursuing job and career opportunities for mothers came after a length of time of devoted energy to their families, followed by a realization that other aspects of their lives needed to be fulfilled.

> I want to work, and I want to go back to school, and these are all things that other women and men want to do. I'm getting to the point where I've learned to put my own needs before (others) unless it's a dire circumstance. And (putting my family's needs ahead of mine) probably was appropriate at the time. I think most moms get to that point after awhile. Where they realize that if their needs are satisfied, everything else goes along smoothly. And that was a difficult lesson.

In contrast to mothers whose career opportunities were delayed, fathers experienced disruptions in work or career trajectories as a result of having a child with autism. All fathers were employed but sometimes the choice of work hours was contingent on what was necessary to best meet the needs of the family. At times, the more creative aspects of work were put on hold or relinquished because fathers did not have the time and energy to pursue them, fathers moved to areas that provided the best service for their child even when that was not necessarily the best move for their careers, or advancement was denied given the demands from home.

Coping with fatigue and limited leisure time. The sources of fatigue are many and varied when one has a child with autism. There is fatigue that comes from not enough sleep because your child sleeps only 4 hours a night, wakens easily to any noise, has night frights, or falls asleep easily only to awaken at 2 or 3 o'clock in the morning to "party." The brother of a 6 year old child with autism related:

> Every night he gets up and starts having a party. In the middle of the night he gets up inside of my mom's bed and has a party. IN: What does it mean when he has a party? What does he do? RE: Well, he just walks all over the place, jumps on the bed. He doesn't come in my room at least.

There is fatigue that arises from the constant vigilance of living with a child who has limited ability to make qualitative distinctions, and good judgments about safety; and there is the fatigue that arises from responding to the diverse care demands and concerns that come from the child with autism as well as those from other children and the family as a whole.

> (In relating the daily routine in which the morning is filled with getting her child with autism ready to go to school at 12:00) I like to leave home around 2:00 to go to work. So, (my daughter) goes to preschool and usually I take her up there as soon as I can finish getting myself and her ready to go out in public. I get back around quarter to 1. And then I just sit down and relax for a few minutes maybe or else I clean the house or I do the bills or...something and then I race out the door at 2:00. And then I work until midnight or sometimes later. Lately, I've had a lot of overtime, so I've been pooped. Usually I'm off like Tuesday, Wednesday, and Thursday. And Wednesday mornings he goes for his sensory-motor therapy and then depending on when he's due again to go to the doctors usually he goes there on Tuesday and now we're switching to Thursday. So, sometimes I get one whole day that I actually don't have to go anywhere and I can wear my grubbies or my sweat suit and not put in my contact lenses and who cares if my hair's a mess and not take a shower and just be lazy. And I treasure

> those days. But I can't remember when the last one was. It's been awhile.

The fatigue and burden associated with caring for a child with complex needs was often managed by parents spelling one another. This was a very common pattern of caring seen in every family in the study. Caring for the child with autism was a way of caring for one's spouse as well as caring for one's child. For the most part this meant that fathers relieved mothers of child care so that they could have a break from the 24-hour a day responsibility of "being on."

> DAD: On the weekends I get up and I take (him) for a walk, for about two hours. MOM: And I sleep. DAD: (Child) is gone and the place is quiet. MOM: And I sleep. (The walk route usually would take only about half an hour to do but this child has many rituals along the way that take much time.) DAD: So I just stand around and I wait and I try to prompt him when he's through with his ritual to sort of hustle him along. So, for 2 hours in the morning I take him out. MOM: But (child) is so grateful when he gets home and so is his mother.

For the most part families relied on their internal resources to meet parental needs for rest and leisure. Only two families in this study received regular respite care from other resources, one through governmental sources and the other through the grandmother who was an integral part of the family's life.

If there was diminished time for individual leisure needs, there was also diminished time and resources for couples to honor their relationship as a couple. For the most part, couples were committed to one another and to meeting the needs of their families. Those who were committed partners in care and life were not always partners in fun and intimacy to the extent that one might see in families whose children do not have such complex care demands. It would be inaccurate to say that couples did not care for one another directly. Words of endearment, hugs and kisses, doing special things like cooking a meal, and "insider" jokes and humor were the everyday practices that showed up in narratives and in observations. However, the couple relationship was not in the foreground of the narratives as an ongoing source of gratification.

Having a brother with autism "can be very annoying": Sibling demands and concerns

Two of the siblings in this study were preschoolers, four were school-age, and one was a young adult who had been a young adolescent at the time of her brother's diagnosis. Interview data were obtained from only three siblings, although each was observed within the context of their families during in-home observations. As a result, the discussion of the impact of a child with autism on siblings was undertaken with caution.

Siblings had experienced a range of responses to their brothers affected by autism. For two siblings, each 5 to 7 years older than the child with autism, "annoying" was a gross understatement of the impact the child with autism had on them although "annoying" was the term used by one sibling to describe his experiences. Responses by these two siblings to the child with autism could be described as dramatic in that they had experienced significant disruptions in their lives following the diagnosis. Within two months of her brother's diagnosis, one sibling was diagnosed with anorexia nervosa and experienced months of in-patient and outpatient treatment. At the same time, the father in this family had to move across the country to find work while mother stayed at home and managed the care of two children with severe illnesses. Another sibling, who was very articulate about his thoughts and feelings, was very angry at what he perceived to be his parents' abandonment as they involved themselves in the care of his brother. The family was beginning to address the concerns generated by this child's anger at the time of the study, seeking out a sibling support group and individual counseling. The other five siblings, three younger and two older by 2 to 3 years than their affected brothers, did not express or exhibit the intensity of responses as the two siblings described above, although their worlds were qualitatively different than those of their peers.

The data related to siblings are presented around three central concerns: 1) the response of the sibling to decreased availability of parental time and emotional energy for them; 2) ways in which siblings involved themselves in care or were requested to do so by their parents; and 3) parental concern about responding to the needs of all of their children.

"_See me...see me_". "See me, see me" are the words of one of the youngest siblings in the study and seemed appropriate in conveying the needs of siblings. "See me, see me" means look at me, see what I can do, notice me, love me as much as you love him, protect me, let me make you (parents) proud and happy, and I hurt too. Mother 4 described her sense of her older daughter's distress of the family turmoil.

> In addition to these other kinds of problems she's also really afraid. Like she's got this terrible thing about spiders and she goes and searches the house every night and kills all the spiders she can find. And she will go to extremes and then she'll stay awake until midnight and past midnight. And she's just totally freaking out.

Siblings had many different ways of communicating these needs such as interrupting, "showing off", teasing their brother, being good helpers, and becoming outstanding individuals in their own world. The following exemplar conveys the essence of "see me, see me" through teasing.

> The only way I can describe it, is everything's peaceful. It can be peaceful all day and (older sibling) shows up and 2 minutes later there's this incredible screaming going on. (I ask him) 'What did you do?' 'I didn't do anything.' This whole routine. I mean, I know he's teasing him, and if he thinks I'm not looking he'll do things really overt to get (autistic child) going.

The expertise and subtlety of the teasing is also conveyed in the following exemplar in which the father describes his discovery of a sibling teasing the child with autism to get attention.

> (Both the child with autism, and his sibling who is 2 years younger than his brother, tease one another a lot in this family) (Sibling) would just keep right on going at him. He loved to watch (autistic child) just going to pieces sitting in a chair. So, you know, typical brothers. (Sibling) will sit there and start screaming and gets somebody to come in and start jumping on (autistic child). You've got to really watch what's going on because (sibling) will just do that just so that he can get that, "Aw, I'm being protected by mommy and daddy." They'll be sitting up there on the couch and (autistic child) likes to lay on the couch if he's up there. Well, if (autistic child's) foot brushes (sibling's) clothes it's an automatic scream and it sounds like (sibling) is dying up there.

Siblings as an extension of parental vigilance and care: Being on guard. Siblings took on the care of their brother in ways that extended the arm of the parent in maintaining vigilance and in ways that were an outgrowth of their own unique ways of relating to a child on a child's level. Siblings were often recruited by parents to monitor the autistic child's whereabouts and activities and at other times siblings took up this function on their own. In the following exemplar, Mother 1 describes her 2 year old child as she watches out for her brother with autism.

> (Sibling) tries to help take care of (autistic child) in her own way. She gets him his clothes. She tells on him for doing things. She panics when he climbs the cupboards and tells me. She always wants him to eat something too if I make her something.

In some families, the siblings were expected to assume some aspect of care for the person with autism when the parents were no longer capable of providing care. Because many of the siblings in this study were still very young, plans for long-term care that involved them had not been considered by the parents. However, two siblings (age 8 and 11 years) expressed concern about their eventual involvement in needing to care for their brothers. In the day to day world siblings were expected to learn how to guard against the intrusion of the child with autism into personal belongings or family treasures.

> (During an observation in one home (autistic child) got into the Desitin that was kept in his brother's bedroom dresser drawer. (autistic child) had eaten some of the Desitin and smeared quite a bit more on himself and around the room. As (mother) went to investigate, she said, '(Sibling), age (11 years) you didn't close your dresser drawers. You know better than that.' It seems that all it takes for (autistic child) to stay out of some things, is for the drawer to be closed.)

A unique way in which three siblings from different families were required to be on guard was related to physical attacks, prompted by frustration or anger, from the child with autism. The form of these physical attacks varied from pinching, pulling hair, or hitting the sibling. In most instances parents intervened with the autistic child to stop the behavior, however, in one family the sibling often was asked to leave the room until her brother could calm down.

Balancing care: The ongoing concern of parents

Parents thought they ought to be attuned to balancing the needs of all of their children, when there was more than one child in the family, although they were not always successful accomplishing this ideal. They appreciated the feelings and needs of their non-autistic children but did not always feel as though they had done a very good job at meeting the needs of all of their children. In the following exemplar a father shares his dilemma.

> I wish that I would spend the time with my daughter that I spend with (my son who has autism). Sometimes it's just not possible because of the relationship that a son and his father have. And I think it's more so with (my son). It hurts now when (my daughter) needs the attention she needs.

Another dilemma parents confronted was the balance between teaching their non-autistic children how to adjust and make allowances for the condition that their brother had and when to intervene with the child with autism to put limits on his behavior. In the following exemplar a mother talks about this dilemma.

> (A mother talks about an episode of her son's taking food from his brother's plate) When he's home he gets irritated (with child with autism) "don't steal my food. You stealer." And he does that at the restaurants too, but what I do, I go against, I take's side of (child with autism) and tell (sibling), "Well, if you would eat your food, or protect your plate that wouldn't happen." He doesn't understand that "Why am I taking his brother's side, when (if he were to do the same thing) I would be scolding him?"

Parents managed this dilemma in several ways depending on the individual and family meaning of autism and the way in which they engaged themselves in care. In some families siblings were always expected to make allowances for their brother. In other families parents actively worked to maintain the balance needed between setting limits with the child affected by autism and helping siblings understand that sometimes allowances needed to be made for their brother that would not necessarily be made for them.

Individual Involvement in Care

The individual meanings of autism for parents and siblings has been addressed under care demands and concerns. Given a background understanding of these meanings the individual ways in which family members involved themselves in care will be described. Although some of the caring practices described were observed more consistently in some family members than in others, there was no one style of involvement that was characteristic over time. Rather, the way in which parents involved themselves in care was associated with the care demands and concerns of the situation as well as personal background meanings. Five distinctive ways of involvement with care were identified: engaged care, always on, parent-centered care, care for the moment, and advocacy care.

Engaged Care

Engaged care has been described by Wrubel (1985) and Chesla (1988) as a way of being involved with care such that the person is deeply solicited by the needs of another. In this case, the essence of engaged care is that both parent and child are participants and contributors to the caring relationship. A sense of warmth, concern, and reward from parenting stands out in this way of involvement in contrast to "always on" where a sense of work and drain related to parenting is conveyed. Parents involved in engaged caring practices did not give up part of themselves in the caring. This is not to say that they did not get tired, need a break, or in other ways wonder about their situations. It is to say that they appreciated the demands as well as the shared pleasures and rewarding possibilities of family life.

The essence of engaged care is difficult to capture in words without sounding sentimental. It permeates all aspects of being a parent with the ultimate driving force being to respond, provide, teach, and discipline the child as well as interact with those who care for him in a way that always has his, theirs, and your best interests at heart. These parents had a large "bag of tricks" in being able to take on a situation with a good blend of care and work. In the following exemplar, a mother describes her way of taking on the inappropriate teaching practices of her son's teacher.

> ...the teacher wasn't real sure what to do with him. She didn't want him to cry in the classroom so she sat him in the corner and made him look in a mirror and sit there and watch himself cry. And I came in and (saw) that one day and I said, "This does not work. I don't want him sitting in here crying in front of a mirror." And she said, "Well, I don't know what else to do with him." And I said, "Have you offered him an alternative activity if he doesn't want to do what the group is doing?" And she said, "No. I want him to participate in the group." And we had a hard time with that. I worked out a texture box which, he liked playing with beans and rice. I used to keep them in jars and he'd dump them out to play with them. So we put that in a big dish pan and she said he'd start crying the minute he came in the door...when he come in the door, (I told

> her) "Put his hands in this box and let him play in it and then let him (sit down with) the rest of the kids. Show him where you want him to be." And that worked out, and after (the morning) she was gone for the rest of the day and (once again he was back) sitting in the corner crying. So I had to go back into the classroom and then I kept a good eye on him because I knew things were going bad. He was coming home and I could tell he'd been crying during the day. And then we worked out bubble water and he got to play in bubble water after the texture box.

Developing and using existing practical knowledge, common sense, or intuition were common to this way of engaged care. The parent's capacity to "read the child", watching the child in order to better understand how the child perceived the world, his response to management strategies, and how to interpret his world; imagining oneself in the child's place; incorporating play activities into teaching; and coming to understand what soothes the child were all aspects of engaged care. Siblings also responded with this kind of care when they took time to teach new skills, spend time, and play with the child with autism. The central concern of parents involved with care in an engaged way was that their child with autism was first and foremost a child. Their involvement with caring was a natural extension of how they saw themselves as human beings and was an opportunity for challenge and reward.

Even with engaged caring practices, parents experienced ambivalence about their situation. The most devoted of parents still experienced the push and pull, the hot and cold, the involved and detached stance of living with a child with autism. Discussing care in this way is not intended to label such care as good or bad, but rather to think about ambivalence as a usual experience of family members. The simultaneous and contradictory thoughts and emotions that family members experienced toward the child with autism were clear in the interview data although expressing the ambivalence was more comfortable for some than for others. In the following exemplar a mother who has a very engaged way of being involved with her son responds to a question of what it's been like to be the mother of a child with autism.

> Does the word hell mean anything? (sigh) Confusion, anger, self-doubt. At times hatred...anxiety...A learning experience. Not necessarily a positive learning experience. (pause) But even through the bad times when I was ready to as I have often said, 'flush him down the toilet' I have realized that nobody else is going to do for him.

Always On

"Always on" describes a way of caring that is a response to the need for unending vigilance or physical and emotional state of alertness related to various demands and concerns. Involvement with care in this way was observed often in parents for whom the meaning of autism was a demanding call to duty, and implies a sense of burden and responsibility. Parents were always alert to the activities and whereabouts of their child as well as to new possibilities for treatment strategies. "Always on" as a way of involvement with care showed up in the narratives when the rewards of caring seemed elusive, or the demands of care seemed particularly great given the resources of the individual or the family. There was a sense on the part of the parent that she or he was always giving and seldom getting. Being "always on" meant that parents were deeply solicited and engaged in their child's care but they did not always derive a sense of pleasure from the caring. Wrubel (1985) has described this underlying concern as one of self-care in balance with care for others. Father 7 conveys the essence of "always on" in the following exemplar, and it is to him that I am indebted for making this aspect of care stand out.

> You don't really want to hang out with other parents with autistic children, because we have so many things wrong with us. I mean, we're highly stressed (because of living with a child with autism)...If you could imagine yourself..with normal children and the whole thing and there are probably sometimes in a week...a day...where you can go away and you can have some quiet time. For most of us, that doesn't exist...The other thing that goes along with that, is that we never, like normal people, we never come down. We're always right on the edge. We have to be primed to act at all times because we never know when we'll have to.

This vigilant stance was so much a part of family life in other study families and became so much a part of my understanding of how families manage their lives that without this father pointing it out to me, it might have remained invisible. The essence of being "always on" is that the solution to the situation of having a child with autism resides within the parent (or the family) and his or her ability to interpret, identify, prescribe, and anticipate a number of concerns and to respond accordingly. The emphasis is on structuring the environment and learning activities in a way that minimized the danger and maximized the potential for progress of the child. The descriptions of involvement with the child could be described as outside-in, in that "doing for" the child and a sense of work are conveyed in contrast to engaged care where "doing with" the child and a sense of relationship is conveyed. The central concern of being "always on" was survival of the child. For many parents "always on" as a caring practice was most evident when parents shared the differences of caring for a child with autism and their expectations of parenting or their experiences with other children. That is to say when there was a breakdown in how the cultural and practical knowledge of parenting or children informed experience, parents had to work to find other approaches.

Being "always on" was not an all or nothing phenomenon, although, as with the other individual caring practices, it was more salient in some parents than in others. Although "always on" is described here as most often pertaining to parents, it was also observed in siblings as suggested in the previous section on care demands and concerns related to siblings.

Parent-centered care

Parent-centered care was an involvement with care in which the needs, goals, and projects of the parent took precedence over those of the child or family. This way of caring was somewhat more in evidence among those parents whose explanatory accounts were not based in a strong organic rationale. For those parents for whom autism was a quandary or a religious experience, these explanations of autism characterized by vagueness or attributed to a spiritual being seem to have left parents with their own agendas as a guiding force for involvement with caring. These parents were emotionally connected with their children but their caring practices sometimes missed the mark or were based on the parent's needs rather than the child's. For some, this meant a heavy emphasis on getting the child with autism to conform to a parental expectation of good behavior, similar to the cultural understanding of autistic behavior as representative of "bad children", or an emphasis on socializing the child in such a way that he would not stand out as being different. Pleasurable activities were taken up based on what the parent enjoyed or liked to do rather than what the child with autism enjoyed.

It is not inherently wrong or negative for parental projects to take precedence over those of children. Parents are human beings for whom many things matter including their work, their children, and their individual pleasures in life. What is of concern is that if a child is consistently second in line to the agendas and projects of the parents or caring approaches that miss the mark, the child is set-up to fail in some way. Parents were solicited by their children but they were often frustrated at the child's lack of progress given their parenting efforts. The most striking examples of parent-centered care involved thoughts of reorganizing the family by considering institutional placement for the child with autism or removing themselves from the family.

> Wonderful (at times to be my son's parent) and other times it's terrible. There are times when I'd like to walk out the door and never come back. I've thought of that lots of times.

For those parents who remained in the family, their involvement with the child was usually secondary to that of the other parent. Their care was more indirect in nature in that they supported caring efforts through their involvement with work (outside and inside the home) in contrast to direct intimate involvement with their child.

In each parent for whom parent-centered care was salient, the personal meaning of the experience of autism was different. For some, the meaning of autism was embarrassment, bafflement, or ineffective parenting, and for others, there was an absence of meaning about autism where one would expect to find special meaning. From a nursing perspective, an understanding of parent-centered care facilitates the nurse accessing the meaning behind the caring practices, which in turn affects the nursing approach. For example, the parent for whom there is no special meaning of autism may need to know more about autism and the nurse may need to help the parent translate the diagnostic criteria and their specific relationship to the affected child. The lack of meaning could be transitional in nature as families "take in" what the diagnosis means for their affected family member. In contrast, the parent for whom autism is an embarrassment or threat to sense of self may also need educational and translational assistance from the nurse and may also need personal care related to the source of embarrassment and threat.

Care for the Moment

Care for the moment was a caring practice which had two dimensions. First, care of the moment involved the initiation of strategies intended to diminish the child's distress. Second, care of the moment is used to describe actions taken to maintain the child's happiness. The child's happiness and sense of well-being was preserved no matter what the cost and sometimes the cost was parental fatigue, disruption in family routine, and demands for siblings to accommodate to the needs of their brother over those of their own. In some families care for the moment was situational or developmental in nature, and in other families, care for the moment had become a predominant caring practice of one or more parents.

Care for the moment is a customary way of responding among many parents of any child and is probably an important aspect of coming to know one's child and feeling competent as a parent. What is qualitatively different about this way of being involved with care was that for some of the children with autism in this study it had persisted much longer than it does in non-disabled children. In addition, for the family of a child with autism, the stakes are higher in that an unhappy child could result in destructive or intrusive behavior.

Infants have no sense of time in that their needs are immediate. Many children with autism have a disrupted sense of time. It is as if they have no "social sense" of time. The meaning of common phrases such as "in a minute", "after awhile", and "in a little bit" was frequently lost on them. In the same vein then, their needs were often expressed with the same urgency that one might expect from a small infant, and perhaps it feels this way to the child with autism. These needs were often communicated by crying, screaming, or producing other frustrated and anguished sounding noises, sounds that traditionally tell us that a child is urgently distressed.

The risk of responding in a manner that does not appease the child is that the child moves into a tantrum. Tantrums were intense family experiences during which the child with autism may yell, scream, pull the hair of others or himself, hit himself or others, bang his head on objects, or respond in other extreme ways. Once a tantrum began it was very difficult for parents, who were often at their creative limits of being able to find meaningful ways of parenting their child, to bring things back into control.

At some point in time though, parents began to make the transition from a stance of wanting to meet the demands or needs of the child with autism at all times, regardless of family cost, to one of setting limits and initiating other strategies that would enhance the child's ability to cope with the frustration of his world. Learning to find the balance of responding to a child's needs is evident in the following exemplars from the same parent. In the first a mother describes the challenge of coming to know her child and in the second her thoughts about how else to socialize him.

> It seems like there's always something that I have to do in order to keep him in his real contained environment, the way he likes it. And to keep his structure going. It's hard to keep the routine for him and that's something I'm constantly trying to change in one way or another just because things always change you know, between the weather and different things like that...
>
> ...like it's easier to give into (my son) than it is to teach him that there are certain things that he can and can't do at certain time. And I've (gotten) to where (my son) has to learn these things and I've just kind of set my foot down and said, "this is the way it's going to be...you can't go out this late, or no, you can't have cheeseburgers again tonight." And then he'll go into his tantrums...(she then describes learning to manage the tantrums).

Care for the moment was an important aspect of everyday care even though the family had begun to set limits around certain of their child's autistic behaviors. In some families, however, care for the moment was such a dominant way of caring that family members had not developed other caring practices that in the long-run could improve the child's skills for living in the world and the quality of family life. Possible interpretations of why family members had a limited repertoire of involving themselves with the child include: a) lack of energy either from fatigue or depression producing a reluctance to disturb the status quo; b) quiet times so few and far between that when they happened parents enjoyed just "hanging out" with their child; c) being so accustomed to the child's and family's routine that family members had not thought to set limits or to approach parenting from additional perspectives.

> The point I'm trying to make is, that we all adjust to our environment and after a short period of time most of what you do in your life appears to be normal. And especially if you don't interface with other people that are in the rest of your community or society. Then what you do, you're world seems relatively normal.

Advocacy Care

Advocacy care involved pleading the case of the child in whatever forum it seemed necessary to do so. Depending on the situation and the personal concern of the parent, a wide variety of advocacy styles were evident, some adversarial and others amiable. Advocacy was most evident in two areas in study families: the need to educate the public about autism in order to increase services and societal acceptance for all children with autism, and the need to obtain services for their child.

An important aspect of advocacy care was related to going beyond the child with autism in the family to address the needs of all children with autism. For some parents advocacy was their specialization within the family. That is to say that while one parent might be more involved with the day to day care of the child, the other found satisfaction in advocating for the child in arenas outside the family. Other parents took on advocacy as an extension or just another aspect of how they viewed themselves as parents. Parents did this in a number of ways, ranging from educating people they encountered in public places to involvement in some form of political activism. A number of parents in this study were on special education boards, were involved in the ongoing work of providing summer programs for children with autism, or were actively involved with fund-raising.

Another significant aspect of advocacy care was obtaining services for the individual child with autism. Most parents approached the need to identify and obtain services for their child from a position of trust. That is to say, that educational, health care, and social service professionals initially were trusted to work toward the child's best interests. If the professional also worked for the family's needs, so much the better, but the bare minimum was that they worked for the child. Parents eventually learned that they could not trust professionals to know about autism, about recommended treatment strategies, or about educational or community resources. Parents learned that, in addition to the day to day care of providing a nurturing environment for their child, they also must "take on" the educational, health care, and political systems in order to see that their child got what he needed.

The maxim most often heard from parents with regard to obtaining attention from health, educational, or political professionals was "you have to fight for everything you get." In the following exemplars a parent elaborates on the maxim and then a mother describes how she and her husband work as a team to get from the school system that which they believe is necessary for their child.

> The (name) school district won't give you anything unless you throw a fit...just really pester the devil out of them and get angry, jump up and down, and then you get what you want, what your child needs.
>
> It's not that they're (school officials) obnoxious or negative or anything. It's just that when you sit at a table and you've got twelve people there, that are advocating for the educational system and you're the only person there advocating for your child. They have usually got a whole lot more facts and ammunition than I do. All I have are mainly my feelings and what I know is best for my child. And they'll throw a bunch of legal stuff. The first (IEP meeting) took place in the classroom and it only lasted like, half an hour and there were three people there. Then my husband started going and all of a sudden, there were like 20 people there. I (think they thought) "this guy is really tough, we'd better pull in our big shots and all our big guns to come in."

What stands out about these exemplars, in addition to the adversarial nature of the encounters, is that from the parent's perspective the professionals are advocating for the school system and parents are advocating for the child. What is also evident in this instance is how undervalued the mother's knowledge of her son seems to her. That this might be so does not seem unlikely in a society where theoretical knowledge is valued over experiential knowledge, and where technological care is valued over human care.

The data suggest that this situation is not unique to the school system. In the following exemplar a mother described her experience of taking her child to the hospital for a surgical procedure. In spite of her best efforts to the contrary, she and her son experienced one battle after another about how things were to be done.

> (Prior to the procedure) I planned for it. I went up there 3 times. I spoke with all the doctors who would be doing it, and I explained to them how (my son) was and how he was probably going to react. We got into the hospital and they put us into his room, and they wanted a bracelet on him. And I told them, "he won't wear a bracelet." And they said, "Well, he has to wear this bracelet." So I said, "He won't put it on. You (have) to wait at least until he goes into the operating room." So they waited and I got him into his room. He didn't want the gown on, he didn't want the bracelet on. And they were determined to put (the bracelet) on him again. They went ahead and put the bracelet on and he just started biting and he got these scratches in his wrist where he tried to pull it off and tear it off, and he started biting it. And he started hitting himself and getting real upset in there. (Mom distracts him and calms him to a "borderline crying" state. After about an hour they move to the pre-op area and Mom is told she must leave him there). And I said, "Well, are you putting him to sleep now?" And they said, "Well, no, you can't be in here." And the whole day was like, I can't be here, I can't do this, the doctors have to do it. And finally I got tired of it and I said, "Well, if I'm leaving, he's leaving with me." And they said, "Okay, you can stay." (Mom goes on to do battle about whether her son will get a pre-op injection and whether she will be

> allowed to accompany her son into the OR suite, both of which she wins). After he had all those cuts on his wrist, we got into pre-op and he cut (the bracelet) off him. They said he never needed it in the first place. I was mad...I'm really learning quickly...that parents do have that right just to say, "No."...And it's a shame though that you have to go through all that, because I know that when (my son) was younger, I wouldn't do it. I trusted the doctors (and nurses), I believed they knew what they were doing.

In this instance, the professional interpretation of this mother might have been that she was difficult, over-involved, or over-protective. Parents who knew well their children with autism were protective of them and had learned that they did not necessarily need to accept the approach of professionals when parental judgement suggested that an alterative approach would be better. The other distressing aspect of this encounter was the perceived unwillingness of the nurse and physicians to listen to what she had to share about her knowledge of her son. From a nursing stand point two important values are at stake when we diminish the knowledge that parents bring to a situation such as this: (a) sensitive care for child and family, and (b) parental trust in present and future health care professionals.

Summary

The care demands and concerns of living with a child affected by autism were multi-dimensional in nature, arising from the affected child, the personal impact on individual family members, and the ongoing search for appropriate professional care. The content of the care demands and concerns of living with an autistic child were not substantively different from what parents of other children experience: safety, communication, social skills, social relatedness, meaningful activities, and the capacity to interpret the world and make progress toward knowing what you want, and getting it. Qualitatively, the experience can be very different from the cultural and experiential understanding of "normal" family life. It is hoped that the translation of the medical description of autism to the family experience of autism will help nurses think of autism as a family experience as well as a medical diagnosis.

The individual meanings of autism to parents and siblings provides another interface for nursing care. The sense of aloneness expressed by many parents was very powerful, and equally powerful were the encounters they had had with others who in some way made a connection or cared enough to become personally involved with the parent. To have someone else care enough to understand was in itself a healing experience. The needs of siblings may go unnoticed in these families because the demands of the affected child or the family may mask the concerns of siblings. In two instances, it took fairly drastic sibling responses for the family to notice that they needed attention also.

Individual involvement with care was related to the central concern of the parent and was situationally and contextually bound. From a nursing perspective, thinking about the way in which parents involve themselves with care opens up new possibilities for nursing care. For nurses to ask themselves, 'What is the central concern of this parent at this particular time?' allows nurses to think about whether the parent is most concerned about themselves, the growth and development of their child affected by autism, maintaining the peace and quiet, controlling the environment to protect the child, educating others about autism, or some other concern not captured by this research. Each of these parental concerns generate unique nursing care concerns and facilitate the taking on of care in a more sensitive, understanding way.

CHAPTER VI

The Family Experience of Autism

Families are comprised of individuals, each of whom bring their own background meanings, explanatory accounts, and caring practices to life with a child affected by autism. The purpose of this chapter is to describe the way in which these individuals live together and care for each other as a family. Toward this end, the family meanings of having a child with autism and the family caring patterns will be described. In addition, potential nursing concerns will be included in each description of family care.

Family meanings and caring patterns are presented as themes observed within more than one study family. Using a thematic analysis captures the meanings, experiences, and caring practices common to some if not all of the study families. Paradigm cases, an alternative strategy for illustrating particularly strong instances of family meanings and family caring, are not included in this report. The use of paradigm cases was rejected for two reasons: (a) The investigator could not guarantee confidentiality to study families, and (b) there was concern for conveying the notion that families organized themselves around care in only one way. Every attempt has been made to strike a balance between maintaining individual and family confidentiality and the loss of meaning that can result from removing or smoothing over background meanings. Background meanings such as who constituted the family, descriptions of family environments, potentially identifiable personal background meanings, and some of the nuances of caring practices have been eliminated from the presentation in order to obscure family identity.

Family Meanings

Yalom (1980) defined meaning as the intent behind an expression. The search for meaning then is an attempt to make sense of a situation or experience the individual has encountered. This study does not address the question of the process of finding meaning by individuals or families. However, that individuals and families had found meaning in the experience is communicated in the interview data. The family meaning of autism does not imply that everyone in the family believed the same thing or involved themselves with care in the same way, although in some families this was the case. The term family meaning is used to capture an interpretation of the essence of autism in the family. Family meaning addresses such questions as how has the family made sense of having a child with autism, is there convergence or agreement among family members regarding the meaning of autism, is the family meaning consistent with how others might view the family situation. Understanding the meanings of autism within the family was an important aspect of understanding the purpose, aim or intention of family care. In the following, the words of family members, or interpretative phrases are used to identify themes intended to capture family meanings of autism. As with individual meanings and caring practices, there was no one meaning that could be specifically identified with each family, and family meanings were not static. In most instances family meanings were derived from reflection on the family as a unit, although it was clear that parents set the tone for the family.

Four family meanings of autism were identified: autism generates or highlights the competing concerns within the family, autism makes sense as a moral obligation, autism changes family life forever, and "it's not so bad". As Yalom's definition suggests, understanding meaning is an attempt to understand the essence of what is conveyed by an action. The boundaries between family meanings and care were often blurry in that through reflection on one, it was possible to gain insight into the other. Given the definition of meaning, the blurriness of the boundaries was not unexpected. As each family meaning is described, exemplars may include descriptions of care as a means of illustrating a particular meaning.

Autism generates or highlights competing concerns within the family

Having a child with autism in the family may exert a dual effect on the family as a unit, and is analogous to the metaphor of a double-edged sword. In other words, autism produced or brought to the foreground competing concerns of individual family members, as well as other pulls and tensions of living in a family. Autism pushed the questions of who was most vulnerable in the family, and who had the most power. Other competing concerns that were visible when there was a child with autism in the family included: the need to know about autism and the need to deny anything was wrong with a child; the wish to balance the needs of a child with autism, the needs of other children in the family, the needs of parents and the needs of extended family members; the desire to parent and the desire to have meaningful work outside the home; the need to receive attention, care, and love and the need to give the same; time for relaxation when none may exist; and the relief that may come from finally knowing what is wrong with your child only to find that new and initially unfamiliar care demands have been created.

Each family exhibited this affect of autism to some extent and in some way, and in most families the disparities were negotiated on an ongoing basis. In other families, the strong distinctions and disparities in individual meanings and involvement with care was prominent and a working compromise had not yet been worked out, or attempts to do so resulted in an ongoing atmosphere of tension and conflict. In one of the study families the parental differences showed up in their personal background meanings, philosophies of child care, meanings of having a child with autism, and central concern of each. Based on her family of origin experiences and early childhood the mother in this family believed that she was "born to care." In contrast, her husband's early childhood and family of origin experiences suggest that his life has been spent learning how to survive with minimal parental involvement. For the mother, autism was a challenge, for the father autism seemed to be a threat or an intrusion on his time. The mother's central concern was for her son and the father's seemed to be for himself. Their differing child care philosophies are conveyed in the following excerpt.

> (My husband) thinks (our son) should be able to go out back and play just because he's got the lock out there and can't get away, but I think he still needs some supervision. And (I feel) the same (about his brother's need for supervision). (It's) not because he's handicapped, but because he's a child and he should have a parent out there. Not just to supervise, but to help interact and to push him on the swing and help him go down the slide. And I even get into the little swimming pool with him during the summer. And the neighbors say, "Oh, that looks like fun."

Living with the ongoing demands and rewards of having a child with autism brought out the best in some family relationships and the worst in others. The double-edged sword of autism sometimes meant strengthened ties between certain family members while ties with other family members were weakened or sacrificed. In many instances the couple relationship took a back seat to meeting the ongoing care demands of all the children in the family. A number of factors contributed to the couple relationship being put "on hold" and included: lack of affordable appropriate child care, lack of financial resources, or a stated lack of desire or trust to place the child with autism in the care of another so that the couple could honor their relationship.

In other instances the bonds between one parent and a particular child (often the child with autism but not always) became very strong to the exclusion or diminished involvement with other children in the family. As described under individual care demands and concerns parents for whom this was an issue were not unaware of their actions or of the affect on their other family relationships. Parental "over-involvement" or "over-protection" has been described by researchers as a dysfunctional family adaptation to living with a developmentally disabled child. In the sense that the needs of other family members may be sacrificed, this was a difficult and problematic family situation. The term "dysfunctional adaptation" implies that the response of the individual to the situation is idiosyncratic, and perhaps that the appropriate intervention would be to somehow lessen or diminish the parent's involvement with the affected child. The focus of intervention becomes one of the amount of appropriate parental involvement. The parents in this study who identified themselves as involved with their children affected by autism at the expense of diminished attention to other family relationships had significant personal background meanings, primarily with their families of origin that could provide a focus of nursing concern. These parents were not responding to their situations in isolation, but rather were embedded within a significant family history that strongly influenced their everyday involvement with their families of today.

Autism makes sense as a moral obligation

The meaning of autism in some families was that autism created a challenge to some deeply held and valued religious, philosophical, or personal convictions. There was intense dedication to these principles and the challenges they created. This meaning was most salient as a family meaning rather than an individual meaning when family members shared the same moral convictions. These families were very dedicated to their children and their moral convictions were significant background meanings that conveyed a standard to be lived up to. What was most at stake then, was not being able to live up to the standard which they had set for themselves or was implied given the particular moral conviction. Herein lies the challenge, the sense of obligation, and the self-doubt about whether they could continue to live up to the expectation.

Two distinct sources of moral obligations were identified in study families and included what Yalom (1980) has described as cosmic meanings and secular personal meanings. Cosmic meanings are those related to living life guided by the tenets of a particular religious affiliation. These tenets can be as circumscribed as the particular scripture of a religion, or denomination within a religion, or as nonspecific as a general faith in God's overall purpose. The belief that "God wouldn't give (us) any more than He knew (we) could handle" was a significant family meaning in one of the study families.

The second source of moral obligations arose from what Yalom (1980) has described as secular personal meanings. Secular personal meanings suggest a belief in an overall order to life and one's role or purpose in relation to that overall purpose. In a sense, individuals and in this instance families, constructed their own meanings and then committed themselves to fulfilling the meaning. Parents set the tone and nature of the moral obligation and when there was more than one child in the family, other children were encouraged and drawn into participating in the overall goal.

Altruism and devotion to a cause are two secular meanings used to describe family meanings in this study. Altruism is defined as intentions or actions designed to leave the world a better place. The data suggest that this was a significant factor behind parental practices to educate others they encountered about autism, to participate in program development for persons with autism, and to volunteer time toward many aspects of promoting the overall welfare of persons with autism.

Devotion to a cause can take many forms such as political, familial, or religious. The essence of being devoted to a cause is that it lifts an individual outside of himself, and in some way makes him a participant in the greater scheme of things (Yalom, 1980). The causes identified by study families included: dedication to advancing the family (including extended family members), dedication to the growth and development of the children in the family, dedication to advancing the scientific understanding of autism, and dedication to developing resources for persons with autism and their families. Entire families, including siblings and extended family members, participated in the activities associated with these causes. As with individuals, families with a cause were lifted momentarily out of the constant presence of autism while at the same time participating in something that would potentially make the day to day living better.

Professionals, extended family members, or friends who witnessed the work of the family and the toll it seemed to take often suggested institutionalization as a source of relief for the family. The thought of institutionalization did not engender a sense of relief for study families; rather, institutionalization was to be avoided at almost any expense. For these families, institutionalization meant a failure to live up to or meet their moral obligations. From the family's perspective, compliance with professional suggestions or dictums at times increased their sense of deficiency in being able to live up to their moral convictions. In the following exemplar, the suggestion of respite from a professional was rejected by a father. For this father, placing his son in respite care was analogous to not liking his son, and very contradictory to his philosophical beliefs that "you don't throw children away like we do everything else in our society."

> (The professionals) were concerned that we were not accessing as much respite as we needed. (They implied that) we "needed respite." "No, I don't need any respite except from people who try to push things on me." They were kind of pushing (my husband) to access more respite and to send (our son) to babysitters and stuff. (My husband) finally whirled around on them and he said, "Look. I happen to like my son. Yes, he has problems, but I like him. I don't really mind being around him anymore. I'm okay. Don't worry about it." They were very concerned that we were not having enough time to ourselves or for each other. And it was kind of like, "Would you guys get off of this theme? Please, we obviously aren't ready for it. Don't make us say it again. When we're ready, we'll let you know.

It seems imperative to identify the moral obligations underlying care in families and to understand that they may be religious ("God wouldn't give us more than we could handle, but sometimes I wonder"), philosophical ("Philosophically we don't throw things away"), or personal ("No one will ever love him like I do"), for each set up different demands for nursing care. Moral obligations and a belief that caring efforts provided a source of immediate or future reward often sustained family involvement in care. Identifying an underlying moral obligation is another way for the nurse to access the meaning system of the family, and another way to base nursing care on that which is important to the family.

Autism changes family life forever

The data suggest that the period around diagnosis, both prior to and immediately following, was a time of vulnerability for families. The diagnosis of autism and coming to understand the meaning or implications of the diagnosis was a family event and was described as stressful by most parents in the study. Autism permanently changed family life. As described previously in Chapter V (The individual parental meanings of autism) understanding the meaning of autism meant coping with a deep sadness and at times depression, revising notions of being a parent, rethinking career and work goals, and coping with ongoing fatigue. Siblings coped with diminished parental attention, and ongoing personal and social intrusions into their lives. Financial stability or security was threatened constantly in many families. Grandparents and other extended family members responded in a number of different ways including withdrawal, expression of concern and feelings of helplessness in knowing how best to assist the family, recommendations of institutionalization or advice regarding "better discipline", and regular involvement with the family in a supportive way. In two families the diagnosis of autism threatened the continuity of the family in that there was concern on the part of one parent that the other parent might leave the home as a way of coping with the diagnosis.

The intensity with which family life was changed varied among study families. For some, as the following excerpt demonstrates, the change was experienced as a severe blow.

> We all went nuts. Got depressed. We lost our desire to keep our other children happy. We lost our sense of humor (laughing). We stopped fooling around. We sort of had this misery without hope. Once we accepted that we had misery without hope, then we just sort of had misery. And misery is better if it's just misery and it could be worse if you had no hope...because misery without hope is probably the next thing closest to death. So, you know, misery is not so bad. Misery without hope is awful.

The fact that autism was a blow implied that the family had grasped a meaning of autism that seemed overwhelming to individual family members and to the family as a whole. Day to day functions of the family were attended to but there was a labored quality to daily activities as if the weight of the world were on their shoulders. Families varied in terms of how long they experienced autism as a blow, but eventually they came to understand that autism was manageable as they placed their experiences with autism within the context of a larger meaning system.

The ongoing day to day family life when living with a child affected by autism meant a disruption to smooth functioning within the family. For families in the study, this was or had been a very demanding way to live in the world. Most families operate on the basis that there are a number of aspects of daily life that are predictable.

Family routines and rituals as well as the routines of individual family members allow individuals and families to move through situations in a fairly smooth manner. This was also true for families of children with autism in that routines provided structure to their lives.

> During the week things are much more structured. (Our son) gets up, we all have breakfast, we get dressed, everybody goes to school, (child) goes to speech therapy, he goes to school. He goes to sensory integration, whatever it is that he has to go to; I take him. Usually the end of our day is about 3 or 4 o'clock and he's tired by then.

However, as described previously under care demands and concerns, at any moment this daily routine might be interrupted precipitously by the activities of the child with autism. In addition to the constant family vigilance necessary to monitor the activities of the child, there were a number of other aspects of family life that could not be taken for granted. If families attended church they found they could not take their child to the usual Sunday school classroom. Going to movies required special planning as demonstrated in the following excerpt shared by the father of a 9 year old child with autism.

> Generally speaking we take him anywhere we go, but we have to be more careful at movies. Especially late shows as opposed to matinees where kids yap yap anyway. (We have tried matinees with him on a couple of occasions) and it's worked fairly successfully but then usually one of us has to go out and (be) with him out in the lobby for like 20 minutes of the movie. Which is not always a lot of fun because you're missing the damn movie.

Many parents of young children experience similar situations when they attend a movie. What was different for these families was the ongoing nature of needing to make special accommodations for one's child. Eating out in restaurants was often an adventure in dining pleasure. In the following exemplar a father talks about the family shifts they have made around eating out.

> I think there's a lot of tension..it's like there's questions, do we ever take him out again? Do we want to go through this again? And I think the biggest thing that we've realized is that we eat home, we either have the food brought to us, or we'll go out and get it through the drive-up, and this is the way we do it if we're going to eat out. Or we try to eat at home more often.

Family vacations became almost non-existent or separate vacations became a way to best meet the needs of all the family members. In several families, holidays and other family celebrations were not spent with certain members of the extended family because of intergenerational disagreements on how best to manage the child with autism.

Families were challenged in a number of ways in efforts to enhance their sense of family because just doing the things that families traditionally do together were not smooth functioning processes. Because families were embedded within a culture in which autism is invisible to some and misunderstood by the majority, some families chose to withdraw from some aspects of public family activities and replaced them with family activities at home such as movies on VCR's and take-out dinners. In spite of the obstacles, families had found ways to foster and promote a sense of family through family routines and rituals that had evolved out of past and present family traditions and experiences.

"<u>It's not so bad</u>"

In contrast to a family meaning of autism that suggests a change in family life forever, was the family meaning that the diagnosis of autism was "not so bad." Based on a theoretical understanding of autism (most often from college courses) or their interpretation of what they were told by the diagnostician, autism was something that could be managed, treated, or cured given the right parental involvement or treatment strategies.

> (In my college class) we were not exposed to the long-term significance of autism. We were really led to believe that this was a condition that could be compensated for and even normalized. Which, is not true, you know. That's something that I had to learn last year and that was pretty disappointing. When I first heard that (my son) had autism, I really wasn't that concerned. I figured that he would have a lot to deal with and that we as a family would have a lot to deal with. But I didn't understand just what exactly the significance would be.

As suggested in this excerpt, the diagnosis of autism was viewed initially as well within the capacity of the family to manage, and, for this parent, the meaning of autism gradually changed to incorporate a number of permanent changes for her family. In two of the study families, "not so bad" was the current family meaning of autism.

As described above, to many of the study participants and families the diagnosis of autism in their child meant a change in their assumptive world (Parkes, 1971). That is to say, the diagnosis initiated a change in one's view of many things previously taken for granted, such as the smooth functioning of every day life, ideas about parenting and family life, and one's own future life plans. In families for whom autism was "not so bad" this change in the assumptive world had not taken place in one or more family members.

When the expression of autism in the child was not extreme, the diagnostic period was prolonged and ambiguous, parental background understanding of autism was inconsistent with what they saw in their child or the current scientific thinking about autism, parents did not seem to understand the implications of the diagnostic label. Some parents were relieved to get the diagnosis because it meant that they were not the cause of their child's problems, while others thought that autism could be easily managed. In either case the interpretation was that there would be minimal impact on parenting, usual family routines and other aspects of every day living. This minimization of the meaning of having a child with autism became a family meaning rather than an individual meaning when both parents shared this view or when one parent who seemed to understand the immediate and long-term implications of autism acquiesced or passively supported the spouse's minimalist view.

For some families this was a transitional period of time similar to the dawning awareness described by Kodadek and Haylor (1988) where parents gradually take-in the ways in which their child experiences the world differently. In other families, where this meaning was salient long after the diagnostic period viewing autism as "not so bad" sustained hope and in some ways kept the family together. For one family member, to "accept" a meaning of autism held by many around him that his son would always be affected by autism meant giving up or quitting in terms of searching for a cure or hoping for recovery. This hope may in some way sustain this parent's involvement in the family and nursing care of the family would need to take this particular meaning into serious consideration.

Family Care

The definition of caring that guided this study was that of Benner and Wrubel (1989) and is grounded in Heideggerian phenomenology. Caring, or having things matter, means that people, events, and projects outside of the self are important. A caring stance is one in which the focus of concern is outside the self, rather than on the threat any particular person or thing may hold for the self. This is an individual view of caring that is being applied to families. Families are groupings of individuals with a shared public understanding of what is. It is the interpretation of the shared understanding of what is important in the family that will be described briefly. Then, in more depth, the ways in which study families involved themselves with care will be described.

An important aspect of describing family care was to address the question of who within the family seemed most vulnerable. Another way to address the question was to ask, "Who within the family had the most at stake?" Understanding who was most vulnerable or had the most at stake helped identify who was the focus of care and whose concerns were considered most important and study families varied considerably with regard to this question. The child with autism was the focus of caring in two families. In these families, parents viewed their child with autism as extremely vulnerable and in need of the majority of their time and energy with the result that other family relationships were compromised or sacrificed. In three other families all of the children in the family were the focus of care or were those who seemed most important. In these families parents worked hard to find a balance between the time and energy consuming demands of having a child with autism and the demands of their other children. In the remaining two families, a parent was the individual who seemed to have the most at stake or be most vulnerable, and family care was organized around the vulnerability of the parent.

Another important aspect of understanding family caring practices was to identify the events or projects that were important to the family. For study families, events that mattered similar to the events that might matter in any family and included time alone for individuals and couples, peace of mind, family traditions and celebrations, job promotions, finding meaningful work, and success in school. Important events for study families not experienced by other families included signs of progress in the child with autism, a day without tantrums, an uninterrupted night of sleep, or encounters with a hostile public.

Study families had many projects of importance, many of which were related to the child affected by autism such as participating in finding a treatment or cure for autism, developing services for children with autism, becoming politically active, and the day-to-day activities of promoting development and progress in the affected child. Family oriented projects included raising happy children, advancing the well-being of the family, raising well-disciplined children, and finding a way of meeting the needs of all family members and the family as a whole.

The ways in which families took on those persons, events, and projects of importance was truly unique within each family. However, there were common themes or ways of thinking about family care that went beyond the boundaries of any one family. Four themes of family caring practices are presented below: adversarial care, convergent care, business as usual, and care arising from despair. Each description of family care will include a description of who was most vulnerable in the family, the projects of importance to the family, the family meaning, and the related nursing concern(s) generated by each.

Adversarial Care

Adversarial care means that family members were often in disagreement with one another regarding who was most vulnerable within the family, and which projects were most important. The family meaning most often associated with this way of being involved with family care was "autism highlights or generates conflicting concerns within the family." The overall tone of the family was one of conflict and when the conflict was unresolved the family ceased to function as a family around the issues related to care.

Central to this way of family care was the question of who was most vulnerable, or who had most at stake in the family and between which family members did the disagreements occur about the question. For example, if for one parent caring for a child with autism was an extension of one's altruistic nature, and for the other parent the meaning of autism was a threat to one's self-esteem, the central concern of each parent would be very diverse. In some families the discord was between the parents with children experiencing the fall-out. The tension created by competing concerns regarding appropriate discipline for the child with autism is conveyed in the following exemplar.

> (My son) will go into his tantrum and come to me to pinch me and I'll grab his hands and say, "No! You don't pinch me." And I'll see him run to his brother and I'll grab him again and say, "No, you don't pinch." And then he runs to (his dad) and I'll say, "This one is up to you." And he lets him pinch him and he'll slap his hand and tell him "No" and (my son) will pinch him again. And then (Dad) will smack him on the bottom or something and send him to his room. And (my son) will come back and pinch him again. And (his dad) will usually just leave (the room) and that upsets him even more. (Younger sibling) has gotten to where he sees (child with autism) going for (dad) trying to pinch him and he'll say, "No, no.." And then when (dad) will try to stop or spank (child with autism) or something (sibling) will say, "Daddy, quit. Quit, Daddy."

In other families the tension lived between the parent(s) and one or more of the children. The following exemplar is representative of how one sibling in the study expressed his feelings that he did not receive the parental attention he wanted.

> (Mom was encouraging (sibling) to share his thoughts with her. In response (sibling) entered into a bargaining session which expressed his underlying concern for himself and his own needs) Sib: I'll tell you what I want. You can't love (my brother) for one week. Mo: No, I have to love him honey. Sib: Okay then I won't tell you what I was going to say.

Power struggles were common experiences in this kind of family care and often revolved around whose projects were most important such as appropriate disciplinary strategies or maintaining one's power base within the family. Understanding the competing concerns depended on the explanatory accounts and personal background meanings of the autism for the family members in disagreement. In some instances there were contradictory explanatory accounts and in others the personal histories of the individuals or the personal meanings of the autism were so disparate that negotiation of the meaning gaps was extremely difficult.

The particular expression of adversarial family care depended on the extent and qualitative nature of the disparities about the explanatory accounts and personal background meanings of the individuals. Escalating power struggles were significant events in adversarial family care. When the power struggle existed between parents and children, the parent set the tone for care, as adults are usually acknowledged as having more power than children. Even in these instances, though, children had their own ways of influencing caring practices within families such as that described under the care demands and concerns of siblings.

Several nursing concerns were possible in families with a great deal of tension. When competing concerns were divergent and remained unresolved they had become a chronic source of irritation, fatigue, and unhappiness for the family. Whether this was a predominant theme within a family or an episodic theme within the family, the family atmosphere of adversarial care was one of great swings in mood, affect, and orderliness. One risk under these circumstances was that the family would be reorganized in an attempt to alleviate the distress. In several families reorganization through divorce or placement of a child outside the home had been strongly contemplated. Reiss, Gonzalez, and Kramer (1986) have described the reorganization of the family as one extreme way in which families attempt to cope with the long-term demands of having a chronically ill member. This attempt at reorganization is a result of prolonged, although not fully self-aware, ongoing disruption of daily routines and relationships produced by the chronic illness. A second nursing concern regarding adversarial care in families was the potential for family violence, either in the form of child abuse or spousal abuse. Although no specific instances of personal injury of family members were observed or related during data collection, instances of conflicts that escalated into violent behavior on the part of one or more family members were related.

Convergent Care

Convergent care implies that on some level within the family there was a certain amount of agreement regarding who was most vulnerable within the family, the projects of import, and the family meaning of autism. For the study families this meant that the needs of the child with autism, or when there was more than one child in the family, the needs of all the children in the family were of primary importance. This is in contrast to other family care in which care was organized around the needs of one of the parents. As a result, the projects of most concern were related to the growth and development of the children, and the family meaning of autism was related to a deep sense of moral commitment and the ongoing work of managing the permanent changes to family life created by the autism. Family members were not always in agreement with one another but when disagreements arose the conflict was out in the open. Differences of opinion were not ignored or kept underground, nor did they provide the impetus for escalation as they might have with adversarial care. Given these commonalities, there was also expressive divergence between families, "Doing it all", Specialized care, and "Do your own thing" and these are described in more detail below.

"Doing it all". "Doing it all" describes family involvement with care that has as its goal meeting all the needs of individual family members and the family as a whole. The central concern of families who "do it all" was meeting the standards they had set for themselves as a family. Although individuals within the family were engaged and solicited by the child with autism, there was a heavy sense of obligation communicated and less communicated pleasure or enjoyment from family life. The ongoing tensions of the family often centered around issues of equity regarding who had done enough, and of what.

"Doing it all" parents attempted to pursue all promising avenues of treatment for the child with autism. This pursuit involved the ongoing evaluation of scientific literature and information gleaned from other parents, identifying treatment strategies and sources of care, and taking the child for appointments. At the same time it meant trying to have enough time, energy, and financial resources to meet the special needs of other relationships in the family such as dental and vision care, college for children, and celebrations and special outings for the couple or family as a whole. It could be said that in some instances "doing it all" care was more focused on doing things for each other rather than doing things with each other. In this sense "doing it all" as a family caring practice is analogous to the individual caring practice of "always on."

The risks of long-term caring in this way without respite included stretching or breaking the family budget, depleting the physical and emotional energy of the parents, and neglecting the individual and couple needs of the parents. The family's plate was often full and unexpected demands were difficult if not impossible to take on or manage. For families who were solicited by meeting their own expectations as parents and less so by involved engagement with their child the rewards of caring were often elusive. It is difficult to know how one is meeting a standard when you are the only one who can evaluate your progress. On the rare occasions that someone noticed the family's efforts and commented on their good work there was cause for really feeling good about life.

There were a number of factors that contributed to this way of family caring. In those families where the disease process model of autism was predominant and the care demands of the child with autism were such that caring responses from the child were minimal, involvement with care in this way was common.

Specialized care. Specialized family care refers to a way of being involved with care that draws on the special talents of each of the individuals in the family, particularly the parents. For instance, in one family the mother's individual caring practices were engaged while the father's usual involvement with care was one of advocacy. By developing expertise in different areas, perhaps parents could better cope with the unpredictability of family life. The central concern of specialized care was to provide for the needs of family members and the family unit but with the realization that it was not possible to "do it all". Families took on care in a similar way that a business might in that each parent had a specific area of expertise and care efforts were coordinated, negotiated, evaluated for their effectiveness, and decisions made about which ones to keep and which ones to discard. Although there were areas of specialization of care, there was also overlap. For example, both parents were involved with the day to day world of the child with autism but one parent had more responsibility in this area than another. At the same time, both parents were involved with other aspects of care such as advocacy or bringing in money to support the family but the primary responsibility or involvement with these rested more with the other parent. The following exemplifies the way in which the work of the family gets done with specialized care.

> I try to do as much as possible when (my son) is in school, you know shopping and laundry...cleaning. (My husband) takes care of most of the household bills and stuff. He's much more on top of things than I am (about that).

The child with autism, as well as other children in the family, received the benefit of both approaches to caring. Often this meant that mothers were more involved in the day to day world of the children. Fathers were involved with more distant care such as work priorities on a day to day basis, with more involvement on the weekends around recreational activities and home projects.

The tensions of family life centered around finding the proper balance of being "always on" and having leisure and alone time, "fighting for everything you get" and finessing the system, and differences in parental beliefs about treatment strategies for the child with autism and disciplinary strategies for other children in the family.

Specialized family care seemed to work fairly well especially when everyone in the family had an equal voice. The risk was that parents became overly specialized without having the opportunity to learn from each other. In some families there was ongoing concern for what would happen in the family should one of the specialists be unavailable or incapacitated.

"Do your own thing". "Do your own thing" as it describes involvement with family care is similar to specialized family care in that each of the parents had areas of expertise as well as overlap. In contrast to specialized care though, the central concern of "do your own thing" was the maintenance of individuality while meeting the needs of the child with autism. Taking care of yourself and thereby reducing the already high demands on the family was a way of taking care of the family. At the same time the family was relatively self-reliant for meeting its own needs having experienced a lack of understanding for their experience from friends and various professionals. It was better to set your own course, make your own mistakes, experience your own rewards, and care for your own children than to expose your vulnerability, and have it misunderstood or thwarted by those one should be able to trust. The goal was to live up to no one's standards but to respond to the individual needs of the family given the resources available. Outside resources were not always available or were available only if one was willing to pay the emotional and mental price that came with obtaining them, thus the need to be able to rely on yourself.

Care of the child with autism was a joint venture for the parents and the one individual in the family whose needs were attended to above all others, for the child with autism had the most at stake and the fewest resources to meet his own needs. Each parent was involved with the child in their own individual way, and there was very little push for either parent to take on the caring practices of the other or diversify their approaches.

Having worked out this way of family caring, family members seemed content with it. From the outside-in perspective of the investigator it seemed lonely and isolated at times. There was a deep long-term commitment to preservation of the family with this way of caring. However, a potential risk to the family members and the family unit of "doing your own thing" over time was increased emotional and social isolation.

Each of these unique expressions of convergent family care raise different demands for nursing care. The moral convictions underlying involvement with care and ongoing family efforts to manage the demands of care also come with their own rewards. Usually these rewards were related to being able to see the fruits of the family's labor. Perhaps the greatest nursing concerns for these families are to support the ongoing caring practices of the family and help them avoid burn-out such as that described by Marcus (1977, 1984).

Business as Usual

"Business as usual" means carrying on the work of the family as if members of the family did not have special needs. The hope was that the autism would go away, wasn't as bad as everyone was telling them, or could be fixed and eliminated as a problem in spite of significant evidence to the contrary. The central concern of the family was to sustain a self-image of normal family life. There was hesitancy to deal with conflict and at times conflict was underground. Not everyone in the family operated as if there was nothing wrong in that outside resources were obtained for the child with autism. Within the family, though, there was the illusion of business as usual. In this way of family caring, one or both of the parents had a parent-centered approach to parenting and the family was organized around this ambivalent position. As with parent-centered caring practices of individual family members, "business as usual" for the family was transitional in some families and a prolonged way of being for others. When the central concerns of parents were different, one parent through passive acknowledgement agreed to participate in the denial of the child's long-term disability. They passively agreed to disagree, and the family meaning of autism was that "it's not so bad." The person with the most at stake in this way of family caring was usually the parent who was in a quandary about autism and engaged in parent-centered caring practices. The risk of being confronted with the denial about the circumstances meant losing the power struggle or being personally defeated. Knowing this, other family members seemed to go along while at the same time doing what they believed best for the child.

What differentiates "business as usual" from "doing your own thing" is that in the latter there is a shared desire for minimal interdependence and maximal independence between family members and between the family and the larger community. In "business as usual" there is an illusion of intimacy and family when in actuality there is a fair amount of individualism in approaches to care for the child with autism and the family as a whole.

Under these circumstances, "business as usual" sustains the family. A nursing concern of "business as usual" is that family members may not be able to express themselves openly. The risk of confronting the ambivalence and the quandary of the explanatory account of autism too directly is in forcing the family to look too closely at themselves, they may crumble as a family.

Care arising from despair

To despair means to lose hope and confidence and by definition implies despondency. The family meaning associated with care arising from despair was that of autism permanently changing the family. The family had grasped this meaning and their response was one of being overwhelmed by the implications. Not all families in this study reported experiencing despair but for those who did it was a very troubling and difficult state to endure. Families in despair could be described as sad, lacking in energy, and discouraged. As with other family meanings, family despair was transitory in some families and more long-term in others.

The focus of care for those families in despair, without exception, was the child with autism to the exclusion of other family members. The project of highest priority was the development, progress, or cure of the child with autism. When there were other children in the family, the needs of siblings were experienced as an additional burden or demand to the parents who were already overwhelmed by a child with a severe developmental disability.

Sustaining hope in some way was a central factor in moving through despair. For some families hope was sustained by seeing progress in their child and when progress was minimal or absent, hope was difficult to sustain. For some families contact with other families of children with autism helped them move through despair. The opportunity to see other families mourning the impact of a child's autism on the family helped some realize that they had moved through the despair. Getting through the experience of feeling overwhelmed, depressed, sad, and angry about the child's diagnosis provided hope and reassurance for families that they were capable and strong in having come through the struggle.

The most central nursing concern in working with families in despair may be the prevention of the complications that arise from depression that endures over time, such as suicide, withdrawal from life, or possible family dissolution. When there seem to be insurmountable circumstances, limited hope, minimal progress from the child and the impact of which of these circumstances is a deep sadness in one or more family member, the risk of suicide cannot be discounted. Another nursing concern arises out of the inability of the family to care for all of it's members. Parents are human beings and as such vary in terms of their ability to attend to the needs of themselves and other family members in any given situation. All children benefit from caring relationships with their parents and other significant adults. In the event that parents are not able to attend to the needs of themselves or other children in the family, nursing care could include coaching and helping the family to recognize the unmet needs and then to assist with finding ways to meet those needs.

Summary

In this chapter family meanings, family care, and the nursing concerns generated by each have been explored. Four family meanings and patterns of family care were described.

Autism generated or highlighted competing concerns between family members that often created situations requiring problem-solving, negotiation, and flexibility. In the process of resolving the competing concerns, an atmosphere of turmoil, conflict and tension was often generated. Some families were able to resolve these situations when they arose with a minimum of distress. When competing individual concerns were extremely disparate, and remained unresolved an atmosphere of conflict and tension permeated the family experience and escalated into adversarial caring practices.

Families who made sense of autism as moral obligation had given a lot of thought to autism and the purpose it played in their lives. That they had found meaning that seemed manageable and resonant with the personal background meanings of individual family members seemed helpful in that family care was supported by complimentary meaning systems. Convergent care, family care based on complimentary meaning systems among family members, was expressed in different ways in study families and three of these caring patterns were described: "doing it all", specialized care, and "do your own thing."

Autism changes family life forever as a family meaning implies two messages: a) Autism is a family diagnosis, and b) Family involvement and change takes place over a lifetime. As the families came to understand the implications of this meaning some reported feeling overwhelmed and the resulting care has been described as care arising out of despair. Some of the study families had had more experience with coming to terms with this family meaning and their caring practices are described under convergent care.

A family meaning of "it's not so bad" suggests that the family has rejected or is inattentive to a meaning of autism as something that changes family live forever. The family's attempt to deny this particular meaning of autism, created the possibility for caring patterns described as "business as usual".

The family meanings and family caring patterns described in this chapter are not mutually exclusive categories of meaning and care. Each created different nursing concerns and possibilities for care that have not been exhaustively explored here. Ultimately, the way in which an understanding of these family meanings and caring practices may influence practice lies with clinicians and their involvement with families.

CHAPTER VII

Implications

What are the implications of a phenomenological interpretive study of families with children affected by autism for nursing theory, research, and practice? In Chapter I, a statement was made indicating that this study would generate interpretive theory or an explanation of a phenomenon in meaning terms and that an interpretive understanding of family caring would enhance current theoretical knowledge of family stress and caring. It was also stated that the study would provide a different basis for the development of a caring partnership with families on the part of nurse clinicians than that which might be generated from current theoretical understandings of family care. Finally, it was anticipated that this study would provide the basis for further research regarding nursing interventions that would be sensitive to the individual and family meanings, thereby avoiding a flat approach to nursing practice. In this chapter each of these contributions or possibilities of the study toward advancing nursing theory, practice, and research will be explored.

Implications for Nursing Theory

Current theoretical formulations of family response and adaptation to a child with autism, such as the Double ABCX Model (McCubbin & McCubbin, 1982), have used a number of concepts demonstrated empirically to predict family health.

These concepts and variables include social support, meaning of the child's disability, family resources, problem-solving ability, marital satisfaction, maternal depression, and pile-up of other stressors. Although there is an acknowledgement of the contextual and dynamic nature of family processes, traditional theoretical formulations of family care have been conceptualized as a decontextualized linear phenomenon. Subsequently, they have often been measured using traditional research methodology such as paper-and-pencil instruments. One result of this approach to knowledge development about families of children with autism is theory that provides a flat road map as the basis for learning and practice.

The philosophical and conceptual underpinnings of this study called for an approach to research methodology in which data collection procedures were interactive in nature and contextually embedded in the lived experience of families. As a result, the interpretive account is more like a topographical map of family care. The findings of this research support previous work in the area regarding the relational, recreational, financial, and personal impacts of a child's disability on the family. In addition to understanding specific areas for clinical assessment of families, this study offers a glimpse at what the experiences of these impacts look and feel like from the perspective of family members. In this study family adaptation was not viewed as a product of problem-solving, social support, and positive interpretation of the meaning but rather family adaptation was viewed as a thoughtful, emotional, action-packed phenomenon. Family adaptation was conceptualized as a process in this study.

One of the most striking aspects of family life revealed in this study, often obscured in studies with more traditional approaches, was the courage of families who take on the day to day care of their children, persevered in the face of isolation, and found enjoyment and pleasure in their situations. The depth of their caring, their expertise in managing difficult situations, their ability to maintain a sense of humor, and the moral commitment to do everything possible for their child and families were remarkable.

Findings of this study add depth to concepts, such as social support, currently used to examine family coping. Family members in this study revealed that they may actively seek social support from other families, friends, churches, and extended family. They also shared that unless there was a human connection, unless there was expressed concern and care from those sought out, the social support was of limited value. If these families were asked to respond to the Family Crisis Oriented Personal Evaluation Scales (F-COPES) (McCubbin, Olson, & Larsen, 1987), a research instrument designed to measure active family coping through assessing family resources, pile-up, and meaning/perception, they might be described as low in social support. The items related to social support only ask whether the family member seeks advice, encouragement, and support from friends and family. It does not ask if the support is there once families share themselves with others.

Based on their research experience Bristol and Schopler (1983) identified three meanings parents may give to the experience of caring for an autistic child: 1) the child is seen as a burden impeding family progress; 2) the child is viewed as a punishment for previous family transgressions; or 3) the child's presence is taken as a challenge and opportunity to learn new skills. Evidence of these three meanings were found in this study although they do not represent the extent nor capture the depth of meaning expressed by family members.

Meaning systems in three specific areas were explored in depth in this study: Meanings related to the individual family members' explanatory accounts of autism, meanings related to the individual care demands, and meanings related to family care demands. The explanatory accounts of autism were described as a permanent organic condition, an organic disease process, a quandary, and a religious experience. Individual meanings of having a child with autism evolved within relationships and in this study included challenge, embarrassment, crisis, devastation, reward, a sad mystery, no big deal, and a commanding call to duty. Family meanings included: Autism highlights or generates competing concerns within the family, autism makes sense as a moral obligation, autism changes family life forever, and "it's not so bad." The central concerns and caring practices associated with these meaning systems were then described. Individual and family meaning was conceptualized and investigated in this study as a contextually bound, culturally embedded, personally influenced phenomenon. In contrast, meaning within family stress theory has often been defined as the individual or family perception of the capacity to solve problems.

This interpretive description of family caring reveals the dynamic multi-dimensional nature of caring in families. Family caring is not a flat linear process. If formal theory is the regression line of common experience, then phenomenological research is the variance about the regression line and, to some extent, captures the common as well as the unique experiences. Family members had different central concerns unique to different aspects of care and for many the common denominator was to do every thing reasonable or possible to enhance the growth, development, and happiness of their child with autism. In this, they were like many other parents.

The textured experiential aspects of explanatory accounts, care demands and concerns, individual and family meanings, and individual and family caring practices were explored in this study and interpretive theory was generated. The interpretive phrases used to describe caring in families of children with autism were generated from the every day language of families and those of the investigator. It is hoped that by diminishing the distance between the lived experience and the language of description, that the meaning of the descriptors will be more readily recognized.

Implications for Practice

In general, an interpretive account of family caring creates new possibilities for practice. In this instance, it provides a means of interfacing with families and not a template for prescribed care. Interpretive accounts can sensitize the nurse as a human being to the suffering and pleasures of families and encourage nurses to use emotional, intuitive, as well as thoughtful caring practices. It is hoped that this interpretive account provides numerous possibilities for nursing access with individuals or family units.

Many of the specific implications for practice of family stories have been addressed within each of the chapters related to the study findings. In general, the implications of understanding explanatory accounts, individual care demands and concerns, and family meanings and care are related to enhancing the nurse's ability to enter into a caring partnership with the family. Benner

(1984) described seven domains of nursing practice, three of which (helping role, teaching-coaching function, and organizational competencies) are particularly relevant for developing and sustaining this caring partnership with families of children affected by autism.

Family stories created many possibilities for nurses engaged in a helping role. The sense of abandonment, fatigue, and isolation expressed by parents and siblings emphasizes the need for helping families identify outside resources as well as the importance of the presence of the nurse who personally witnesses the individual and family experience. One of the risks for siblings is that given the everyday care demands of a child with autism, sibling concerns may seem "normal". Parents may not recognize or may not know how to attend to the needs of other children, and may need assistance interpreting the concerns of siblings. Preserving the human experience, a key aspect of the helping domain of nursing practice, in the face of professional or societal objectification of persons with autism, and participation in sustaining hope and involvement with care are central nursing concerns with these families.

The process of accessing individual and family meanings, such as that used in obtaining information about explanatory accounts, demands, and concerns of individuals and families in this study, is an important clinical strategy for nursing, an aspect of the teaching-coaching function of nursing (Benner, 1984). By staying with the individual and family physically and existentially the nurse in practice participates in a powerful caring experience. Once the nurse and family have made a connection based on common meanings the nurse can facilitate the translation and interpretation of illness experiences through empathic listening. In education, I am in agreement with Kleinman (1988) when he suggests that we must promote the development of the ability of clinicians to interpret individual and family experiences and not pass those students who fail to demonstrate these skills just as we would for lack of other "objective" knowledge.

Finally, the interpretive account of individual and family caring presented here has implications for the organizational and work-role competencies of nursing practice. Families consistently expressed their frustration and anger resulting from interactions with professionals who were misinformed or uneducated about autism. These encounters increased the work of the family and contributed to their overall sense of isolation. Nurses, as well as other professionals involved with persons with autism, have a responsibility to educate themselves, their colleagues, and the public about autism. A great deal of scientific literature exists related to autism and it is constantly changing. Many family members were very knowledgeable about these scientific advancements, while others struggled to make sense of the literature and the implications for their child. If nurses are to help families evaluate the constantly evolving knowledge base regarding autism, they must have an adequate knowledge base and a beginning understanding of how to evaluate research reports.

Because autism is not a well known condition and professionals may have limited exposure to these children, perhaps it is unrealistic to expect each and every professional encounter to be one that is based on mutual knowledge and understanding of autism. What is possible, however, is for professionals to stay open to the clinical situation and to take the lead in bridging the knowledge gap. By acknowledging and involving parents, the people who know their child best, nurses can initiate a caring partnership rather than a call to battle. In most battles someone must win and someone must lose. It would be my contention that when we as health care professionals set up the possibility for battle over the care of a patient, everyone loses. To miss an opportunity to enhance a patient's sense of competency and well-being is to miss the opportunity to care, a phenomenon that for patient and nurse long outlasts any health care encounter (Gadow, 1989). To miss an opportunity to learn from parents about autism creates the possibility for repeating and enforcing the need to do battle because we continue to operate from an uninformed, uninvolved position of care.

Implications for Research

The implications of this study for further research are related to the methodological and ethical issues of interpretive research with highly visible vulnerable families, and extending the current work. First, I will address the methodological and ethical issues that arose in the course of this study. Second, I will discuss ideas for further research in this area based on the findings of this study.

Ethical and methodological concerns.

For the most part, families were very receptive to study participation, although, as noted earlier, two families withdrew prior to the beginning of data collection. In the community from which this sample was selected, many families knew one another which created a number of ethical and methodological concerns throughout the study.

During data collection and the course of participating in the lives of study families, family members would often refer to other study families in the course of their conversations, knowing that the investigator also knew of the other family. I had to be careful not to inadvertently disclose confidential information, e.g., knowing the other family in question, and accomplished this through listening or vague responses to questions one family might pose to me about another family. During a brief visit to the home of one study family, I walked into the living room to find two other study participants sitting in the living room. One of the mothers said, 'Oh, here are all of your people', meaning, those she knew that had participated in the study.

Another ethical concern that arose during the course of data collection, particularly during in-home observations, were the disciplinary actions used by parents that were physical in nature and counter to what the investigator might consider appropriate or effective. The extent of physical punishment was spanking and no abusive situations were encountered, therefore no direct intervention of the investigator was needed. However, sometimes it was difficult to witness such disciplinary measures. Following one interview session, an abusive situation was revealed to the investigator involving an extended family member. The study participant was advised that if during observation in the home of the extended family member any evidence of abuse was detected that I would be required by law to report the abuse. Subsequently, no abuse was noted during observation and the study participant and investigator had a lengthy discussion about future need to report child abuse and her willingness to do so.

The overall ability to maintain confidentiality within families and between families was an ongoing concern. Methodologically, interpretive research relies on the use of exemplars and paradigm cases to support and give life to interpretations. As discussed in Chapter VI, paradigm cases were not included in this report because of the high recognition possibility among study families who might read the final report.

Finally, situations arose during data collection that required the investigator to abandon temporarily the research role and to assume a clinical role. In each instance, continuation of the study was negotiated and in one instance data collection was curtailed.

Future research. This is a beginning phenomenological look at caring within families of children with autism. Although a number of family experiences have been described and interpreted, I am also aware that there are family experiences that have not been captured in this study. Therefore, further phenomenological study of more families is warranted. At a future point in time a comparison of phenomenological findings and findings based on quantitative methodologies of family coping could prove fruitful in furthering our understanding of current concepts being used to study families.

The data related to the experience of siblings were limited in this study and their experiences varied widely. Some seemed to be doing quite well, while others were expressing considerable anger and a sense of abandonment due to parental involvement with the child affected by autism. Present knowledge regarding a sibling's lived experience in a family with an autistic child is limited and warrants further research.

Further investigation of the impact of meaning based nursing interventions are also warranted. Throughout this report potential implications of meaning based care have been made, however, these can be considered speculative at this point until further research is done. For example, in what way does eliciting illness accounts influence the family's perception of care, their competence as a family, or the long-term effects of disability? Can the concept of "breakthrough" be used as an effective nursing intervention with individuals or with families? How does the language of nursing diagnosis reflect the way in which nurses involve themselves with family care? What are the nursing interventions best suited for family care described as adversarial, convergent, business as usual, and care arising from despair?

Limitations

The conceptualization of caring as a personally and culturally embedded phenomenon accessed through interviews and close observations designed to capture its cognitive, emotional, and embodied expressions created methodological challenges not fully anticipated prior to the research. Central to each aspect of data collection and analysis was the experience and expertise of the researcher. Although I had participated in two interpretive studies prior to this project, this was the first research project for which I was the principal investigator, primary data collector, and central analysis person. As such, I learned a great deal about staying focused during interviews and observations regarding the essence of what I was seeking, i.e., rich detailed descriptions of individual and family meanings and caring patterns. Monitoring my own reactions, some of which were unexpected, to individual and family experiences encountered during data collection was another important aspect of data collection. The assistance of my committee, colleagues who served as analysis consultants, and a mental health consultant were invaluable in developing my skills as an interpretive researcher which are now more developed than they were at the beginning of the research.

The personal involvement of the researcher is essential in interpretive research. Getting involvement right has been noted as an important aspect of expert clinical nursing practice (Benner, 1984; Benner & Tanner, personal communication, March, 1990). Getting involvement right, i.e., enough involvement to have access to the meaning world of study families, and being able to assume a reflective stance when necessary, were difficult aspects of data collection. Inexperience with respect to involvement with research participants could be viewed as a limitation of the study. Although interpretive sessions and regular meetings with a mental health consultant were components of analysis that addressed this concern, it can never be known with certainty how my level of involvement with families influenced the study findings.

Summary

The interpretive descriptive study of families of children affected by autism explored the explanatory accounts of autism, individual care demands and concerns, and the family meanings and caring patterns of families of children affected by autism. The purpose of elucidating the interpretive accounts of individual and family meaning systems and their relationships with caring practices was to produce "action sensitive knowledge." In other words, one of the primary purposes of interpretive research is to create thoughtful and tactful clinicians and perhaps researchers as well. Whether this purpose has been accomplished remains to be seen for it is possible only to say that the interpretations, as presented here, create possibilities for nursing practice. Clinicians, families, researchers, and theorists must continue the dialogue with the text and respond accordingly.

References

Akerly, M. (1984). Developmental changes in families with autistic children: A parent's perspective. In E. Schopler & G. Mesibov (Eds.), The effects of autism on the family (pp. 85-98). New York: Plenum Press.

Allen, J., DeMyer, M., Norton, J., Pontius, W., & Yang, E. (1971). Intellectuality in parents of psychotic, subnormal, and normal children. Journal of Autism and Childhood Schizophrenia, 1(3), 311-326.

American Psychiatric Association (1987). Diagnostic and statistical manual of mental disorders (3rd ed., Revised). Washington, DC: Author.

Behrens, M., & Goldfarb, W. (1958). A study of patterns of interaction of families of schizophrenic children in residential treatment. American Journal of Orthopsychiatry, 28, 300-312.

Benner, P.E. (1984). From novice to expert: Excellence and power in clinical nursing practice. Menlo Park, CA: Addison-Wesley.

Benner, P.E. (1984). Stress and satisfaction on the job: Work meanings and coping of mid-career men. New York: Praeger.

Benner, P. (1985). Quality of life: A phenomenological perspective on explanation, prediction, and understanding in nursing science. Advances in Nursing Science, 8(1), 1-14.

Benner, P., & Wrubel, J. (1989). The primacy of caring: Stress and coping in health and illness. Menlo Park, CA: Addison-Wesley.

Bettelheim, B. (1956). Schizophrenia as a reaction to extreme situations. American Journal of Orthopsychiatry, 26, 507-518.

Bettelheim, B. (1967). The empty fortress. New York: Free Press.

Block, J. (1969). Parents of schizophrenic, neurotic, asthmatic, and congenitally ill children: A comparative study. Archives of General Psychiatry, 20, 659-674.

Bristol, M.M. (1984). Family resources and successful adaptation to autistic children. In E. Schopler & G. Mesibov (Eds.), The effects of autism on the family (pp. 289-310). New York: Plenum Press.

Bristol, M.M. (1987). Mothers of children with autism or communication disorders: Successful adaptation and the Double ABCX Model. Journal of Autism and Developmental Disorders, 17(4), 469-486.

Bristol, M.M., & Schopler, E. (1983). Coping and stress in families of autistic adolescents. In E.Schopler & G. Mesibov (Eds.), Autism in adolescents and adults. New York: Plenum Press.

Bristol, M.M., & Schopler, E. (1984). A developmental perspective on stress and coping in families of autistic children. In J. Blacher (Ed.), Severely handicapped young children and their families (pp. 91-141). San Diego, CA: Academic Press.

Cantwell, D.P., Baker, L., & Rutter, M. (1979). Families of autistic and dysphasic children: I. Family life and interaction patterns. Archives of General Psychiatry, 36, 682-687.

Cantwell, D.P., & Baker, L. (1984). Research of families and autism. In E. Schopler & G. Mesibov (Eds.), The effects of autism on the family. New York: Plenum Press.

Chesla, C.A. (1988). Parents' caring practices and coping with schizophrenic offspring: An interpretive study. Unpublished doctoral dissertation, University of California San Franciso.

Coleman, M., & Gillberg, C. (1985). The biology of the autistic syndromes. New York: Praeger.

Cox, A., Rutter, M., Newman, S., & Bartak, L. (1975). A comparative study of infantile autism and specific developmental receptive language disorder: II. Parental characteristics. British Journal of Psychiatry, 126, 146-159.

Creak, M., & Ini, S. (1960). Families of psychotic children. Child Psychology and Psychiatry, 1, 156-175.

DeMyer, M.K. (1982). Infantile autism: Patients and their families. Current Problems in Pediatrics, 12(4), 1-52.

DeMyer, M.K., & Goldberg, P. (1983). Family needs of the autistic adolescent. In E. Schopler & G.B. Mesibov (Eds.), Autism in adolescents and adults (pp. 225-250). New York: Plenum.

DeMyer, M.K., Hingten, J., & Jackson, R. (1981). Infantile autism reviewed: A decade of research. Schizophrenia Bulleting, 7(3), 388-451.

DeMyer, M.K., Pontius, W., Norton, J., Barton, S., Allen, J., & Steele, R. (1972). Parental practices and innate activity in normal, autistic, and brain-damaged infants. Journal of Autism and Childhood Schizophrenia, 2(1), 49-66.

Dewey, M., (1983). Parental perspective of needs. In E.Schopler & G.B. Mesibov (Eds.), Autism in adolescents and adults (pp. 297-318). New York: Plenum Press.

Dreyfus. H.L. (1983). Being-in-the-world: A commentary on Heidegger's Being and Time, Division 1. Manuscript. Philosophy Department, University of California, Berkely.

Dudziak, D. (1982). Parenting the autistic child. Journal of Psychosocial Nursing and Mental Health Services, 20(1), 11-16.

Eisenberg, L. (1957). The fathers of autistic children. American Journal of Orthopsychiatry, 27, 715-724.

Eisenberg, L., & Kanner, L. (1957). Early infantile autism. American Journal of Orthopsychiatry, 27, 556-566.

Field, P.A., & Morse, J.M. (1985). Nursing research: The application of qualitative approaches. Rockville, Maryland: Aspen Publication.

Gadow, S. (1989). Clinical subjectivity: Advocacy with silent patients. Nursing Clinics of North America, 24, 535-541.

Gilliam, J., Unruh, D., & Haley, K. (1980). The status of nurses' knowledge and beliefs about autism. International Journal of Nursing Studies, 17, 189-195.

Harris, S.L. (1982). A family systems approach to behavioral training with parents of autistic children. Child & Family Behavior Therapy, 4(1), 21-35.

Harris, S.L., Handleman, J.S., & Palmer, C. (1985). Parents and grandparents view the autistic child. Journal of Autism and Developmental Disorders, 15(2), 127-137.

Hauerwas, S. (1986). Suffering presence: Theological reflections on medicine, the mentally handicapped, and the church. Notre Dame, IN: University of Notre Dame Press.

Holroyd, J., Brown, N., Wikler, L., & Simmons, J. (1975). Stress in families of institutionalized and noninstitutionalized autistic children. American Journal of Orthopsychiatry, 45, 26-31.

Holroyd, J., & McArthur, D. (1976). Mental retardation and stress on the parents: A contrast between Down's Syndrome and childhood autism. American Journal of Mental Deficiency, 80(4), 431-436.

Kanner, L. (1943). Autistic disturbances of affective contact. Nervous Child, 2, 217-250.

Kanner, L. (1948). Problems of nosology and psychodynamics of early infantile autism. American Journal of Orthopsychiatry, 19, 416-426.

Kleinman, A. (1988). The illness narratives: Suffering, healing, and the human condition. New York: Basic Books.

Kleinman, A., Eisenberg, L, & Good, B. (1978). Culture, illness, and care: Clinical lessons from anthropologic and cross-cultural research. Annals of Internal Medicine, 88(2), 251-258.

Knafl, K. (1985). How families manage a pediatric hospitalization. Western Journal of Nursing Research, 7(2), 151-176.

Knafl, K., & Deatrick, J. (1987). Conceptualizing family response to a child's chronic illness or disability. Family Relations, 36, 300-304.

Knafl, K., & Deatrick, J. (1986). How families manage chronic conditions: An analysis of the concept of normalization. Research in Nursing and Health, 9(3), 215-222.

Kodadek, S.M., & Haylor, M.J. (1988). Parents' perceptions of the experience of caring for a blind child. Portland, OR: Oregon Health Sciences University, School of Nursing.

Kodadek, S.M., & Haylor, M.J. (1990). Using interpretive methods to understand family caregiving when a child is blind. Journal of Pediatric Nursing, 5(1), 42-49.

Koegel, R.L., Schreibman, L., O'Neill, R., & Burke, J. (1983). The personality and family interaction characteristics of parents of autistic children. Journal of Consulting and Clinical Psychology, 51, 683-692.

Konstantareas, M.M. (1989). After diagnosis, what? Some of the possible problems around diagnostic assessments. Canadian Journal of Psychiatry, 34(6), 549-553.

Langer, D.H. (1985). Children's legal rights as research subjects. Journal of the American Academy of Child Psychiatry, 24, 653-662.

LaRossa, R., Bennett, L.A., & Gelles, R.J. (1981). Ethical dilemmas in qualitative family research. Journal of Marriage and the Family, 43, 303-313.

Leonard, V.W. (1989). A Heideggerian phenomenologic perspective on the concept of the person. Advances in Nursing Science, 11(4), 40-55.

Lincoln, Y.S., & Guba, E.G. (1985). Naturalistic inquiry. Beverly Hills, CA: Sage.

Marcus, L. (1977). Patterns of coping in families of psychoticchildren. American Journal of Orthopsychiatry, 47(3), 388-399.

Marcus, L. (1984). Coping with burnout. In E. Schopler, & G. Mesibov (Eds.), The effects of autism on the family (pp. 311-326). New York: Plenum Press.

McCubbin, H., & Patterson, J. (Eds.) (1983). Social stress and the family. Advances and developments in family stress therapy and research. Volume I. Binghampton, NY: Haworth Press.

McHale, S., Simmeonsson, R., & Sloan, J. (1984). Children with handicapped brothers and sisters. In E. Schopler & G.B. Mesibov (Eds.), The effects of autism on the family (pp. 327-342). New York: Plenum.

McHale, S., Sloan, J., & Simmeonsson, R. (1986). Sibling relationships of children with autistic, mentally retarded, and nonhandicapped brothers and sisters. Journal of Autism and Developmental Disorders, 16(4), 399-413.

Milgram, N.A., & Atzil, M. (1988). Parenting stress in raising autistic children. Journal of Autism and Developmental Disorders, 18(3), 415-424.

Morgan, S.B. (1988). The autistic child and family functioning: A developmental family systems perspective. Journal of Autism and Developmental Disorders, 18(2), 263-280.

Munhall, P. (1988). Ethical considerations in qualitative research. Western Journal of Nursing Research, 10(2), 150-162.

Noddings, N. (1984). Caring: A feminine approach to ethics and moral education. Berkeley, CA: University of California Press.

Ogden, D., Bass, C., Thomas, E., & Lordi, W. (1968). Parents of autistic children. American Journal of Orthopsychiatry, 38, 653-658.

Parkes, C.M., (1971). Psycho-social transitions: A field for study. Social Sciences & Medicine, 5, 101-115.

Polkinghorne, D.E. (1988). Narrative knowing and the human sciences. Albany, NY: State University of New York Press.

Rutter, M., & Schopler, E. (Eds.) (1978). Autism, a reappraisal of concepts and treatment. New York: Plenum.

Sandelowski, M. (1986). The problem of rigor in qualitative research. Advances in Nursing Science, 8(3), 27-37.

Schreibman, L. (1988). Autism. Volume 15, Developmental Clinical Psychology and Psychiatry. Beverly Hills, CA: Sage.

Sprey, J. (1988). Current theorizing on the family: An appraisal. Journal of Marriage and the Family, 50, 875-890.

Taylor, C. (11985). Human agency and language: Philosophical papers, Volume I. New York: Cambridge University Press.

Thomas, R.B. (1987). Family adaptat6ion to a child with a chronic condition. In M.H. Rose, & R.B. Thomas (Eds.), Children with chronic conditions: Nursing in a family and community context (pp. 29-54). Orlando, FL: Grune & Stratton.

Van Manen, M., (1990). Researching lived experience: Human science for an action sensitive pedagogy. Buffalo, NY: SUNY.

Walker, A. (1985). Reconceptualizaing family stress. Journal of Marriage and the family, 47, 827-837.

Wing, L. (1986). Autistic children: A guide for parents and professionals. New York: Brunner/Mazel, Publishers.

Wing, L., (Ed.) (1976). Early childhood autism: Clinical, educational, & social aspects. Oxford: Pergamon Press.

Wolf, L., Noh, S., Fisman, S., & Speechley, M. (1989). Brief report: Psychological effects of parenting stress on parents of autistic children. Journal of Autism and Developmental Disorders, 19(1), 157-165.

Wrubel, J. (1985). Personal meanings and coping processes: A hermeneutic study of personal background meanings and interpersonal concerns and their relation to stress appraisals and coping. Unpublished doctoral dissertation, University of California, Berkeley.

Yalom, I.D. (1980). Existential psychotherapy. New York: Basic Books, Inc.

Zoltak, B. (1986). Autism: Recognition and management. Pediatric Nursing, 12(2), 90-94.

Appendix A

OREGON HEALTH SCIENCES UNIVERSITY
SCHOOL OF NURSING

Informed Consent Form
May 15, 1990

TITLE Caring in Families of Autistic Children

PRINCIPAL INVESTIGATOR Martha J. Haylor, RN, MN, Doctoral Student
Oregon Health Sciences University
School of Nursing

Phone: 285-5905 (home) or
494-7839 (work)

CHILDREN'S NAMES: ______________________
____
____
____

PARENT'S NAMES: ______________________
____

PURPOSE: The purpose of this research is to understand, from the point of view of individual family members and the family as a whole, the experience of living with and caring for a child diagnosed with autism. We understand that participation in this study could entail up to 40 hours of our involvement.

PROCEDURES: Adult family members and children 6 years of age and older will talk with the investigator 3 to 4 times in our home or some other place of our choosing. We know that the interviews will be tape recorded. In the first 2 to 3 interviews the investigator will talk privately with each of the adult members of the family about her/his understanding of autism, specific instances that have been rewarding or troublesome, and personal and family-of-origin experiences that impact living in a family with an autistic child. Each adult member of the family will talk with the investigator for 30 to 60 minutes each time they talk. At least one interview with the adult/s in the family will be completed prior to interviewing the children over 6 years of age in the family.

Children over 6 years of age will be interviewed by the investigator 2 times. The investigator will talk privately with our children about her/his understanding of autism and about specific instances that s/he has found rewarding or troublesome about being the brother/sister of someone with autism. Each of our children will talk with the investigator for about 20 to 30 minutes each time they talk.

In the last interview, our family together will talk with the investigator. This interview will last about an hour. This interview schedule may be changed based upon the individual and family needs of each family.

The investigator will also spend 2 to 4 hours a week with our family for 6 to 8 weeks. The purpose of the investigator spending time with us is for her to be able to observe us involved in our everyday lives of being a family.

We have had the chance to look at the questions that we will be asked as well as the questions that our children will be asked. We know that we can ask that any question not be asked of any or all of our children. We know that whatever our child/ren share with the investigator will be kept private unless our child/ren reveal/s something that is of potential danger to someone. Each of our children will have the opportunity to decide if s/he wants to participate in the study. We know that all of our family members must consent to being observed in the home or in-home observation will not be done.

RISKS AND DISCOMFORTS: We understand that answering some of the questions in this study may bring forth uncomfortable feelings such as sadness or concern.

BENEFITS: We understand that our family may benefit from talking with the investigator about things that concern us and by becoming more aware of those issues. We know that we may not personally benefit from participating in this study, but by our participation nurses and other professionals will learn more about what it is like for a family to have a child with autism.

CONFIDENTIALITY: This study is being conducted to fulfill the requirements for the Philosophy of Science degree in nursing at the Oregon Health Sciences University. The results of this study will become part of a doctoral dissertation, and will be on file in the Health Sciences Library at the Oregon Health Sciences University.

We understand that no one in our family will be personally identified in the report of this study and no names will be on the forms or transcripts following the interview. Each form and transcript will be identified with a code name. The consent forms will be kept separate from the forms and transcripts and kept in a secure locked place by the investigator. Only the investigator, dissertation committee members, and data analysis consultants will have access to the data. Neither our names nor our identity will be used for publication or publicity purposes. The tape recordings and master list will be destroyed after 5 years.

COSTS: There are no known costs involved with this study.

LIABILITY: This study is supported by a National Research Service Fellowship awarded by the National Center for Nursing Research. It is not the policy of the U.S. Department of Health and Human Services or any agency funding the research project in which we are participating to compensate or provide medical treatment for human subjects in the event the research results in physical injury. The Oregon Health Sciences University, as an agency of the State, is covered by the State Liability Fund. If we suffer any injury from the research project, compensation would be available to us only if we establish that the injury occurred through the fault of the University, its officers or employees. If we have further questions, we may contact Dr. Michael Baird at (503) 279-8014.

We have had an opportunity to ask questions and understand that Martha J. Haylor, RN, MN has offered to answer any questions we may have in the future about the research or participants' rights. We know that we will receive a copy of this consent form. We understand we may refuse to participate or withdraw from this study at any time without affecting our relationship with or treatment at the Oregon Health Sciences University.

We have read the foregoing and agree to participate in this study.

____
Parent/Date

____
Parent/Date

____
Witness/Date

OREGON HEALTH SCIENCES UNIVERSITY
SCHOOL OF NURSING
Informed Assent for Child Participants
May 15, 1990

TITLE: Caring in Families of Autistic Children

INVESTIGATOR: Martha J. Haylor, RN, MN, Doctoral Student, Oregon Health Sciences University, School of Nursing

PURPOSE: The purpose of this study is to understand, from the point of view children and their parents, what it is like to live with someone who has autism.

Name: ____________________________________

I understand that my brother/sister has autism and that nurses and other people who care for my brother/sister and our family are trying to learn more about what it is like for a family to have someone who has autism. I know that taking part in this study means talking 2 times for about 20 minutes with the person doing the study. I know these talks will be tape recorded. I also know that the person doing the study will be visiting my family so that she can see what our family is like. She may observe our family as many as 32 hours over 2 months.

I know that I do not have to join this study or answer any of the questions I will be asked. I know that whatever I say in private to the person doing the study will not be shared with my parents unless the person doing the study is concerned that I might hurt myself or someone else. I know that if she is concerned about these things, she will tell me before she tells my parents. If I decide later that I do not want to be in the study, I can stop. If I do join the study and answer the questions, my answers will be studied by a nurse at the Oregon Health Sciences University to try to help families whose child has autism. My name will not be told to other people who read about this study.

I have been told that some of the questions that I will be asked by the nurse may make me sad or concerned. They might also help me to know about my brother/sister's autism better. This study has been explained to me. I want to be a part of it.

____________________________ ____________________________
Signature/Date Witness/Date

____
Parent/Guardian/Date

Appendix B

Interview Guide: Explanatory Model of Autism

1. Background: Would you begin by telling me when you were initially concerned about ________________? What behaviors did you notice? Why do you think it started when it started?

2. At what point did you seek professional evaluation? What were you told?

3. What were you told about the cause of autism? What do you believe causes autism? What do you think other people believe is the cause of autism?

4. What do you think autism does to your child? How does it affect his/her emotions, the way s/he thinks, or behaves?

5. How severe is ______________'s autism? Do you think it will get better/worse or stay the same over time?

6. What kind of treatment do you think ________________ should receive? (Probes: medications, behavioral intervention, psychodynamic/family therapy)

7. What are the most important results you hope to achieve from this treatment?

8. What do you think your family believes is the cause of autism? Do they all believe the same thing?

9. What are the primary problems that ______________'s autism has caused for you? Tell me what it is like to be the (father, mother) of someone who is autistic.

10. What worries you most about ____________?

11. What do you hope will be in ______________'s future?

*Adapted from Kleinman, A., Eisenberg, L., & Good, B. (1978). Culture, illness, and care: Clinical lessons from anthropologic and cross cultural research. Annals of Internal Medicine, 88(2), 251-258.

Sibling Interview Guide: Explanatory Model

1. Background: The purpose of my talking with you today is for you to help me understand more about autism by asking you to share with me what you understand about autism and how it affects your brother. Would you begin by telling me when you can first remember knowing that your brother had autism. (Probes: How did you know? Did someone tell you?)

2. What were you told about the cause of autism? Who told you? What do <u>you</u> think causes autism? How has your understanding changed over time?

3. What do you think autism does to your brother? How does it work? Does it make him think, feel, or act differently?

4. How severe is ____________'s autism? Do you think it will get better/worse or stay the same as you and he get older?

5. What kind of treatment do you think __________ should receive?

6. If he were to receive this treatment, what do you think are the most important results that could come out of it?

7. Can you tell me what it is like to be the sister/brother of someone who has autism? Can you tell me what it's like for your family?

8. What worries you most about ______________ having autism? What do you think worries your family the most about ________________ having autism?

9. What are your hopes for _________________ as you all get older?

Interview Guide: Family Coping

1. I wonder if you can talk briefly about what the experience of parenting an autistic child has been like for you?

2. I am interested in the kinds of stressful things that happen to people in relation to the care or behavior of their autistic child. Please think of an incident that occurred in the last year that stands out for you as being particularly difficult or stressful in relation to ________________.

   a. In general, tell me what happened.
   b. How did it make you feel?
   c. What led up to this situation?
   d. What did you do?
   e. How did what you did change the situation? How did what you did impact the family? Did your action change the way you felt about the situation?
   f. What else did you consider doing?
   g. Looking back on it now, is there anything you would have done differently?
   h. Is there anything about this situation that you think I should know about, something that my questions have not covered?

3. Could you think of another situation that stands out for you as being particularly stressful or meaningful for your <u>family</u> in relation to the care or behavior of your child with autism?

   a. In general, tell me what happened.
   b. How did you and the other members of the family react? (How did the respondent feel? How does s/he think the other family member's felt?)
   c. What did the family do? (Did they seem to take one unified course of action or were there many courses of action taken?
   d. Did family members agree on what should be done? How was this resolved? Who made the decision? How do you feel about the decision?
   e. How did the family's action change the situation? Change how you felt about the situation? Did the experience change the family in any way?
   f. What do you think led up to this situation? Does it remind you of anything that happened in the past? Do you think the family responded in the same way that it responded to similar situations in the past?
   g. Looking back on it now, is there anything that you

would have done differently?

4. Now, could you think of a situation with your child who has autism that was particularly rewarding, that was warm, caring or satisfying.

   a. In general, tell me what happened.
   b. Did this incident seem to impact the whole family or primarily one individual?
   c. What led up to this situation?
   d. How did you feel?
      How did the rest of the family involved seem to feel?
   e. How did you and the rest of the family express their feelings, in response to this situation?
   f. Was this different from the way you had been feeling about ______________ or your situation? In what ways?
   g. Did you want to change the way you felt in this situation?
   h. Was any action taken?
   i. Is there anything else about this situation that you think I should know about, something my questions have not covered?

**Adapted from Chesla, C. (1988) from the Coping Interview, Stress and Coping Project, R.S. Lazarus and J.B. Cohen, 1977.

Sibling Interview Guide: Family Coping

1. I wonder if you can begin by talking a little bit about what it's like to live with a brother or sister who has autism. (What's different/the same about living in this family than someone else's family?)

2. I am interested in the kinds of situations that come up when you have a brother with autism. I'd like you to think of a particular situation that stands out for you where something that your brother did, or the way he behaved was upsetting, embarrassing, or hard for you in some way.

   a. In general, tell me what happened.
   b. How did it make you feel?
   c. What led up to this situation?
   d. What did you do?
   e. How did what you did change the situation?
      How did what you did impact the family?
      Did your action change the way you felt about the situation?
   f. What else did you consider doing?
   g. Looking back on it now, is there anything you would have done differently?
   h. Is there anything about this situation that you think I should know about, something that my questions have not covered?

3. Could you think of a situation involving your brother/sister who has autism that seemed upsetting to your <u>family</u>.

   a. In general, tell me what happened.
   b. How did it make you feel?
   c. What led up to this situation?
   d. What did you do?
   e. How did what you did change the situation?
      How did what you did impact the family?
      Did your action change the way you felt about the situation?
   f. What else did you consider doing?
   g. Looking back on it now, is there anything you would have done differently?
   h. Is there anything about this situation that you think I should know about, something that my questions have not covered?

4. Now, could you think of a time with your brother who has autism that made you feel really good.

   a. In general, tell me what happened.

b. Did this incident seem to impact the whole family or primarily one individual?
c. What led up to this situation?
d. How did you feel?
How did the rest of the family involved seem to feel?
e. How did you and the rest of the family express their feelings, in response to this situation?
f. Was this different from the way you had been feeling about ______________ or your situation? In what ways?
g. Did you want to change the way you felt in this situation?
h. Was any action taken?
i. Is there anything else about this situation that you think I should know about, something my questions have not covered?

**Adapted from Chesla, C. (1988) from the Coping Interview, Stress and Coping Project, R.S. Lazarus and J.B. Cohen, 1977.

Personal History Interview: Parents

Introduction: The purpose of this interview is to help me get a better understanding of the personal experiences that you have had that impact or influence the care that you give to ______________ as well as the other members of your family.

1. What do you think has had the greatest influence on you in relation to being ________________'s parent? What has helped you the most? Can you think of a particular instance that exemplifies the point you are making?

2. Prior to becoming the parent of a child with autism, had you had any other experiences, either growing up or in your adult life, with children who had autism? If so, how have these experiences impacted your life today? Were there other life experiences that stand out for you as influential in shaping your life today? (Probes: interaction with friends, involvement with support groups, formal education).

3. Would you tell me a little bit about the family you grew up in? How is this family similar to the one in which you grew up? (Probe: religion, education, occupations, affection, problem-solving, delegation of responsibilities). How is this family different from the one in which you grew up?

4. How have _________________'s grandparents responded to his/her diagnosis of autism? How does their response impact your family? What would you change about how they have responded, if anything?

5. What worries you the most about your family?

6. What hopes do you have for your family?

Family Interview

Introduction: The purpose of this interview is for you to add to what I am coming to understand about your family. One of the ways to understand about families is to get a sense of how they carry on the everyday activities of living.

1. Would you begin by sharing with me what a typical day is like in your family?

    a. How do the things that need to be done to meet the daily needs of the family get divided (laundry, shopping, cooking, providing an income, care of children)? Who is ultimately responsible for seeing that everything gets done?

    b. Each individual in the family has special needs (adults and children). What are these and how do they get met? (alone time for adults as individuals or as a couple, educational or special interests/needs of child with autism and other children in the family)

    c. In your day-to-day family life how do you express affection for one another? disagree with one another? Can you think of an example of each of these that you would share with me?

    d. How is life different on the week-ends? What kind of things do you do together as a family?

    e. If you could, what would you change about your day-to-day life as a family? What would you keep the same?

2. How has family life changes since _____________ was diagnosed with autism?

3. How do you take care of each other in this family? What are the things that are important or that matter to individual members of the family? to the family as a whole?

4. What would you change about your family life? What would you keep the same?

5. If you were to take a vacation, leave the children at home and I was going to come and take care of them, tell me what I would need to know to care for them in your absence.

6. How does your family celebrate holidays? Which holidays do you celebrate? Tell me about a specific holiday that is typical of how your family celebrates.

7. Does your family have any traditions such as 'every year we spend a week camping', or 'we always go out to eat to celebrate a special occasion.' Can you tell me about one of these?

Appendix C

CODES FOR CARING IN FAMILIES OF AUTISTIC CHILDREN

M. HAYLOR

CE	Coping episode
CONCERN	Central concern of the individual or family in the situation
DEMAND	Difficulties that arise out of a situation with the autistic child, other family members, or life outside the home. Something with which one must cope above and beyond the day-to-day coping. May also refer to the family as a whole.

Parenting practices

ADVOCATE	Going to bat for a child
COMFORT	Physical and emotional caretaking in response to distressed child
PROTECT	To keep from threatened or possible harm
LIMITSET	Putting boundaries on child's behavior
PLAY	Instances of parent-child interaction in which enjoyment, entertainment is central focus
TEACH	Activities designed by intent or happenstance where parent provides a learning atmosphere or specifically works with a child on a particular task
STRATEGY	This is a large category and will probably provide the basis for much more interpretive work. General category for miscellaneous parenting practices specific to dealing with child's autistic behavior. May be double coded with demand.
PBRKDOWN	Parenting breakdown. Instances where parents' response to the situation escalates the behavior or negatively impacts the child or others in the family.

Family

FAM	References to family routine, traditions
COUPLE	Text related specifically to the adult partners in the household and the nature, quality of their relationship
SIBLING	Any reference to siblings
GRANDPAR	Grandparent response to autism or family involvement
FOO	References to family of origin
FAMCARE	Meeting the needs of all family members
FAMRESP	Family response to demands, needs of living in the family

Background for family caring

PERSKNOW	Personal knowledge. Family member understands the experience of another or is in some way guided to respond to a situation in a particular way based on their personal experiences, i.e. family of origin, other life experiences.
FORMKNOW	Formal sources of knowledge. Could include theoretical or research sources of knowledge as well as what they were told by professionals. Also includes knowledge that comes from TV, movies, lay magazines.
PRACKNOW	Knowledge gained from experience of living in the family and in the world. Includes embodied knowing, intuition, maxims, common sense know-how.
SOCEMBED	Socially embedded nature of knowledge. Knowledge that depends on dialogues with others. May show up most often as what parents share or experience with one another. Discussions of support groups would go here.
LEARN	Discussions of how family members learn to manage/cope with behavior of autistic child or other family member.

Involvement

KNOWCHILD	Knowing the ins and outs of a child, what makes them tick and what their motivations, desires, and needs are as a person.
EMOT	Emotional response to or involvement with autistic child or other family members. Includes the range of emotions including positive regard, love, anger, jealousy, etc.
REWARD	Rewards, positive feelings family member receives from their involvement with the autistic child.

Autism

AUTISM	General discussions of autism, descriptions of how autism is expressed in a particular child. Sometimes will be coded with DEMAND.
EXMODEL	Explanatory model. What the individual or family describes as possible cause of autism in their family member.
DX	Discussions of diagnostic process beginning with initial parental concerns--diagnosis.
HEALTHPRO	Encounters with health care professionals.
SCHOOL	Discussions about school or education professionals
SOCIAL	Interactions with friends or other outside the home related to the autistic child. Includes

	discussions of lack of understanding about autism in general public.
MEANING	Any instance where the reader gets a strong sense of what it means to have an autistic child for the parent, sibling, or family as a whole.
FUTURE	Discussions regarding the trajectory of autism; hopes and concerns about the future.
TX	Interventions for autism
RAINMAN	References to the movie Rain Man
PABURDEN	Things with which parent must cope and descriptions of how they do.
SERVICES	Parenting work related to obtaining services or resources for child and/or family.
PROGRESS	Signs of progress that parents note in their children.

3/4/91

Abstract

Title: Caring in Families of Children with Autism

Author: Martha J. Haylor

Approved: ______________________________
Sheila M. Kodadek, RN, PhD

The purpose of this interpretive study was to describe the personal and social meanings of autism, care demands and concerns of living with a child affected by autism, and family meanings of autism. Further, the relationships between individual meanings, family meanings and individual and family caring practices were described. Participants included parents (N=13) and siblings (N=3) of 7 boys ranging in age from 4 to 11 years of age and affected by autism. A series of individual interviews, one family interview and close observations of families were used as the methods of data collection. Analysis was accomplished using hermeneutic strategies of interpretive sessions, reflective thinking, and reflective writing.

The personal and social meanings of autism were described in two ways: the explanatory accounts of autism and the individual impact living in a family with a child affected by autism. Four explanatory accounts of autism were identified: 1) Autism is a permanent organic condition, 2) autism is an organic disease process, 3) autism is competing explanations, and 4) autism is a religious experience. The unpredictability of the future

and the lack of medical, social and cultural understanding of autism were identified as significant demands on study families.

The care demands and concerns generated from living with a child who is limited in his ability to communicate his needs, establish social meanings and relationships, avoid danger, or participate in the world in a meaningful way were described from the family's perspective. Themes of individual caring practices were interpreted and described as engaged, parent-centered, advocacy, always on, and care for the moment. Personal background meanings of parents and the rewarding aspects of care were discussed in relationship to the way in which they sustained involvement with care.

Four themes of family meanings of autism were identified: 1) Autism generates or highlights competing concerns within the family, 2) autism makes sense as a moral obligation, 3) autism changes family life forever, and 4) "it's not so bad." Family caring patterns generated by these meanings were adversarial care, convergent care, care arising out of despair, and business as usual.

The implications of the study to contribute depth to current theoretical understandings of family coping, to enhance nursing practice by sensitizing clinicians to the meaning world of families, and to research which can provide further insight into meaning based interventions were discussed.