

1999

## Impact of Attention Deficit Hyperactivity Disorder (ADHD) on Parents and Children: What are the Lived Experiences of a Parent with a Child with ADHD?

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IMPACT OF ATTENTION DEFICIT HYPERACTIVITY DISORDER (ADHD)  
ON PARENTS AND CHILDREN:  
WHAT ARE THE LIVED EXPERIENCES OF A PARENT  
WITH A CHILD WITH ADHD?

By

Deborah K. Taylor

A THESIS

Submitted to  
Grand Valley State University  
in partial fulfillment of the requirements for the  
degree of

MASTER OF SCIENCE IN NURSING

Kirkhof School of Nursing

1999

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IMPACT OF ATTENTION DEFICIT HYPERACTIVITY  
DISORDER (ADHD) ON PARENTS AND CHILDREN:  
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DEBORAH K. TAYLOR

1999

ABSTRACT

IMPACT OF ATTENTION DEFICIT HYPERACTIVITY DISORDER (ADHD)

ON PARENTS AND CHILDREN

WHAT ARE THE LIVED EXPERIENCES OF A PARENT

WITH A CHILD WITH ADHD?

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Deborah K. Taylor

The purpose of this study was to seek a fuller understanding of and to identify and describe the underlying themes of the lived experiences of a parent with a child with attention deficit hyperactivity disorder (ADHD). The Husserelian phenomenological and Giorgi methods of research were utilized in this study. Four meanings emerged: 1) discovery, 2) searching for control, 3) struggling for normalization/overcoming obstacles, and 4) hope. The synthesized structural description of the experience that emerged was described as an emotional experience that progressed in stages that were cyclic and ongoing in nature. The data suggests that chronic sorrow, as it has been defined by Copley & Bodensteiner (1987), is a plausible emotional phenomenon in these parents. Clinical practitioners can utilize the findings from this study to plan and implement strategies that will help these parents move toward a response that will allow them to function and cope with their situation.

### Dedication

This thesis is dedicated to my husband, Ed and my daughter, Angela. Their sacrifice, support, and encouragement have been instrumental in the completion of my education. Also, to my niece, Holly, and her mother, Anita, for inspiring me to ask why. And finally, to my mother and father—I know they would have been proud.

## Acknowledgments

I wish to express my sincere appreciation and love to all my family, friends, and co-workers who stood by me and supported me in this long endeavor.

I also wish to express appreciation to my committee members, Lorraine Rodrigues-Fisher, Ed.D, chairperson; Cynthia Peltier-Coviak, Ph.D, R.N. and David Sutton, MD, for their guidance and support.

I also wish to express my appreciation to the parents who so willingly shared their personal experiences with me.

Finally, I wish to extend a special heartfelt gesture of appreciation to Betty Marshall, Hackley Hospital librarian, for her valued research assistance and her friendship since I started this journey.

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## CHAPTER 1

### INTRODUCTION

Can you imagine living in a fast-moving world where sounds, images, and thoughts are constantly shifting and you are helpless to keep your mind on tasks you need to complete? Distracted by unimportant sights and sounds, your mind drives you from one thought or activity to another. For many children, this is what it is like to have attention deficit hyperactivity disorder.

“Attention deficit hyperactivity disorder (ADHD) is the term used to describe children who are inattentive, impulsive, and hyperactive” (Stevens et al., 1995, p. 761). ADHD, once called hyperkinesis, is one of the most common neurologic disorders during childhood and adolescence. “According to the Diagnostic and Statistical Manual of Mental Disorders, 4th ed. (DSM IV) the prevalence of ADHD in school-age children is estimated between 3% and 5%, or greater than 2 million children nationwide” (Buncher, 1996, p. 43).

The impact of ADHD on parents and children may provide an explanation of how the quality of parenting can affect the adjustment of the child with ADHD. Understanding what it is like being the parent of a child who throws tantrums, is full of uncontrolled activity, and does not listen or follow directions is an important aspect of determining this

impact. According to Barkley (1990), “parent-child relationships would influence and be affected by the structural and transactional relationship within the child's nuclear family, extended family, and community” (p. 433).

### Purpose

During the course of a child's development, parents of ADHD children may be confronted with a larger number of behavioral, developmental, and educational problems than those of normal children. The time, demands, and energy required to cope with these difficulties may place an enormous amount of stress on the family. In order for nursing to help these parents, an understanding of what it is like to live with a child who has ADHD is needed.

The purpose of this study was to seek a fuller understanding of and to identify and describe the underlying themes of the lived experiences of a parent with a child with attention deficit hyperactivity disorder (ADHD) through self reflection of their thoughts, feelings, and perceptions related to this experience. The Husserelian phenomenological method of research was utilized in this study.

### Research Question

This study examined, explored, and described: What are the lived experiences of a parent with a child with attention deficit hyperactivity disorder (ADHD)? The phenomenological method of research was selected in an attempt to gather information relative to this question.

### Assumptions

Several assumptions in this study are the basis for validation in phenomenological research. First, “phenomenology accepts the experience as it exists in the consciousness of the subject and duplication of behavior is not expected from duplicate data” (Omery, 1983, p. 60); however, similar meanings of experience may produce similar behavior. Furthermore, findings from a qualitative study although unique to that study, may elicit similar experiences of feelings when read or shared with others because of a shared humanness within experiences. This study was also based on the assumption that the participants’ statements would accurately reflect what they perceived the experience to be and would respond to the research question with reference to their own experiences.

## CHAPTER II

### LITERATURE AND CONCEPTUAL FRAMEWORK

#### Organizing Framework

Phenomenological research is the study of lived experiences and is a way of providing a holistic approach to studying this particular human concern. The birth of phenomenological research is largely due to a philosophy developed by Edmund Husserl (1859-1938). His philosophy of phenomenology was based on his claim that the lived experience was not readily accessible because it constituted what was taken for granted (Koch, 1995). This belief was supported by his criticism of a certain group, “the positivists”, who he felt were influenced by their prejudices which did not allow them to see that there was more information to be gained than what was before them. Their approach, in his opinion, needed to be focused more on the subjective experience (Cohen, 1987; Omery, 1983).

Drew (1993) states that phenomenological research “honors human experience, keeping it intact and in context with descriptions that ultimately draw us closer to each other, connecting us to one another and validating our experience” (p. 345). The researcher is intimately involved with the parent during disclosure and therefore must make every attempt to disregard all preconceived ideas and remain open to the meanings of what the lived experiences might be.

Polit & Hungler (1995, p. 198) describe the four basic steps of phenomenological research:

1. Bracketing: The process of identifying and holding in abeyance any preconceived beliefs and opinions one may have about the phenomenon under investigation. The researcher brackets out notions and presuppositions, in an effort to confront the data in pure form.
2. Intuiting: The researcher remains open to the meanings attributed to the phenomenon by those who have experienced it.
3. Analysis: Categorizing and making sense of essential meanings.
4. Describing: The researcher comes to understand and describe the phenomenon.

Bracketing, the first step in phenomenological research, attempts to “ensure that all available perspectives of a phenomenon are considered in uncovering the nature of the essences of that phenomenon” (Parse, Coyne, & Smith, 1985, p. 22). The purpose of bracketing is to more fully understand the meaning of the phenomenon to the individual involved in the experience (Oiler, 1982; Parse et al., 1985; Polit & Hunger, 1995; Ray, 1990). According to Ray (1990), the researcher’s prior knowledge of the phenomena under study is to be set aside or “bracketed” during the interviews and “unbracketed” during the thematic interpretation of the experiences. In addition, Omery (1983) notes that it is important that “the phenomenon is being investigated as it truly appears or is experienced; a necessary criterion is that the researcher must approach the phenomenon to be explored with no preconceived expectations or categories” (p. 50).

Intuiting is a step that can be particularly difficult to present with precision. Oiler (1981) states that “it is looking at the experience with wide-open eyes, with knowledge, facts, and theories held at bay; looking at the experience with astonishment” (p. 180). According to Spiegelberg (1976) intuiting “is one of the most demanding operations, which requires utter concentration on the object intuited without becoming absorbed in it to the point of no longer looking critically” (p. 659). The researcher has no preconceived operational definitions or precise instructions in which to view the participant’s experiences as a whole other than “opening ones eyes and ears”. Instead, the data gathered are analyzed to understand the experience from the perspective of the participant (Omery, 1983).

Analysis and description are the culmination of insights found in the participants’ descriptions of their experiences (Ray, 1990). Drew (1993) notes that “careful and deliberate attention to the context of a phenomenon means keeping the exploration of it grounded” (p. 347). Using the Giorgi method of analysis, common themes or major ideas begin to emerge as the researcher reads and rereads, dwelling on each participant’s descriptions until inferences can be reduced to meaningful units of expression (Giorgi, 1975). A structural definition of the lived experience is developed and hypothetical propositions are generated through logical abstraction. Conclusions can then be drawn relative to the research question (Parse et al., 1985).

### Phenomenological Research

Phenomenology is both a philosophical movement and a research method in which the purpose is to examine and describe a phenomenon, as they are lived (Munhall & Oiler,



1986; Omery, 1983). "The phenomenological method seeks to uncover the meaning of humanly lived phenomena through the analysis of subjects descriptions" (Parse et al., 1985, p.15). The underlying assumption is that the researcher can holistically focus in on other persons' perspectives and feelings (Dzurec & Abraham, 1986). Omery (1983) states that phenomenology or qualitative research "is an inductive, descriptive research method. The task of the method is to investigate and describe all phenomena, including human experience, in the way these phenomena appear" (p. 50). After identifying the lived experience to be studied, there were several steps in the research process that are described by Swanson-Kauffman (1986) as follows:

1. Locating Informants
2. Interview and data collection: Consents were obtained, interviews were taped, and transcribed later for review. The interview should occur in a natural setting of the informant. The researcher may also keep journals and field notes.
3. Data analysis: The common objective of data analysis is to find common themes among the data. According to Parse et al. (1985), the data analysis method "is rigorous, adhering strictly to a systematic approach"(p. 19). The Giorgi (1975) method, "which focuses on uncovering the meaning of lived experiences through in-depth study of subjects descriptions" (p. 24) was used to analyze the data.

### Significance for Nursing

Nursing can use qualitative research to explore new areas in care-giving systems, human adaptation, nurse-client interactions, and decision-making (Polit & Hungler, 1995). In nursing, people's words, expressions, actions, and gestures when describing their experiences are important factors to consider when making caring decisions. Qualitative research emphasizes the importance of individual lives and experiences. Qualitative inquiry of a parent living with a child with ADHD, therefore, may help to obtain a better understanding of the various coping skills they employ as they live with an ADHD child. Nursing is in a unique position to provide education and comprehensive and empathetic care.

### Literature Review

After the data analysis is completed, a literature review is then conducted. Because it was the researcher's intent to "bracket" out any notions and presuppositions, in an effort to confront the data in pure form (Polit & Hungler, 1995), the literature review was delayed until the data was collected. However, some knowledge of some of the concepts does exist or the research question would not have been asked. Some concepts that might be explored, in relation to the care of a child with ADHD, would be temperament, stress, adaptation, coping, and family roles.

## CHAPTER III

### METHODS

#### Sample Selection

In qualitative research, four types of samples are commonly used: purposeful, nominated, volunteer, and total population (Morse, 1989). For this study, a purposeful sampling was used. When obtaining a purposeful sample, the researcher may select informants based on their knowledge of the research topic (Morse, 1989). A major criticism of a purposeful sample is that it may be biased because of researcher selection. According to Morse (1989) that criticism may be valid—this type of method may “facilitate a certain type of informant with a certain knowledge being included in the study, but that is the purpose and intent of using this kind of method” (p. 125). The participants for this study were selected from an ADHD clinic that serves approximately 400-500 clients, from low to high socio-economic backgrounds, low to high educational levels, and whose ages range from pre-school to adulthood. All potential participants received information about the study via a poster in the waiting room of the clinic. Any persons who wished to participate could do so by contacting the researcher by post card or telephone call. The method of sampling must be appropriate and adequate. "In order to ensure that the sample meets the criteria of appropriateness and adequacy, the researcher must have control over the composition of the sample" (Morse, 1989, p. 123). Appropriateness is determined if

the method used and the sample obtained facilitates understanding of the research problem. Adequacy is ensured by the completeness and the amount of information obtained during the interview (Morse, 1989).

The selection of participants was based on the following criteria:

1. Parent (mother) living with a child with ADHD.
2. Would have the ability to provide a verbal description of their lived experience.
3. Would consent to participate in the study.

To obtain complete descriptions of the phenomena, the data-gathering interviews may be lengthy and detailed; therefore, the sample size can be small. The sample will be considered large enough when redundancies in the descriptions occur (Omery, 1983). An attempt was made to include diversity in the characteristics of race, age, ethnicity, and also include education and economic status. The researcher contacted the informant by telephone and provided a brief description of the study. The researcher followed a prepared script (Appendix A) to maintain consistency in conversation. A face to face interview was scheduled after the person agreed to participate in the study. The research question was presented to the informant prior to the interview, so that they could reflect on the question and be prepared to fully describe their lived experience.

### Setting

All data collection took place at a time and location chosen by the participant. Participants chose to be away from their children. They felt that having the children nearby might be distracting and could have affected the interview.

### Protection of Human Rights

Approval for this study was obtained from the Grand Valley State University Human Research Committee (Appendix B). The research question and the purpose of this study was discussed with each participant. The nature of the study and the amount of participant involvement and commitment were explained. Possible risks and benefits of the study were identified. Although this was not a physically invasive research, if the setting of the interview had included having the child with ADHD present, there was a potential risk to the participant, the researcher, and the interview. Reflecting on past experiences might also have caused some emotional stress for the participant and might have in turn caused emotional discomfort for the researcher.

#### Risks:

Child with ADHD could have gotten into mischief, while interview was ongoing; undo stress on participant and interviewer; interview have been tainted.

#### Methods to Reduce Risks:

Suggest that setting be quiet without children. Reimbursement of childcare would have been provided by the researcher if it had been would needed.

According to Barcley (1990), parents of ADHD children may often feel inadequate, depressed and angry, and also have a poor self-concept as a parent. Many parents who have previously been unsuccessful in managing their child's behavior will have a history of failure experiences. Literally, their child has been "in control". Benefits of this study to the participant were:

Participant feeling relief at expressing their feelings

Participant gaining a better understanding of their child and of ADHD

Participant feeling reassurance; in their parenting skills and the knowledge that there are others with similar experiences.

The researcher obtained a written consent from each participant, answered any questions concerning the study, and provided each participant a copy of the signed consent form (Appendix C). Each participant had the option to withdraw from the study at any time with no effect to their child's treatment or provision of service. Assurances were made to maintain participant confidentiality.

#### Data Collection

Demographic information such as gender, age, race, and socioeconomic backgrounds was collected. Participants were asked to describe their experience living with a child with attention deficit hyperactivity disorder. They were asked to reflect on thoughts, feelings, and perceptions related to that experience. All interviews were tape-recorded. When the participants felt they had completely described their experience, the interview was terminated. The researcher recognized that the length and quality of each interview would vary, but each participant was provided a two-hour time frame for describing their experience. Two days after the interview was completed, the researcher contacted each participant by telephone to determine if the essence of their lived experience had been captured. At that same time, each participant was offered the opportunity to add or clarify any parts of their taped interview

## Data Analysis

“The purpose of data analysis in phenomenology is to preserve the uniqueness of each lived experience of the phenomenon while permitting an understanding of the meaning of the phenomenon itself” (Jasper, 1994, p. 312). Data for the qualitative study of the experiences of a parent living with a child with ADHD were collected using observation, listening and interviewing techniques. The Giorgi (1975) method of data collection as described by Omery (1983) was used for this study. This method incorporates the process of intuiting and of dwelling with the data, analyzing, and then describing the phenomenon under study. The procedures of data analysis were as follows:

1. A description of the phenomena was transcribed verbatim per an interview with the informant.
2. The researcher read the entire description to get a sense of the whole.
3. The researcher thoroughly reread the entire description several times and identified individual units of meaning.
4. The researcher identified developing themes and compared the themes between each interview.
5. The researcher reflected on the themes and transformed the concrete language into concepts of science.
6. The researcher then integrated and synthesized the insight into a descriptive meaning of that experience. It was then communicated to others for critique.

The researcher then compiled the data collection. The participants were identified only by a number on the tape-recorded interviews.

### Validity and Reliability

Validity is generally taken to mean that the study tests what it sets out to test. Sandelowski (1986) states that, "Qualitative research emphasizes the uniqueness of human situations and the importance of experiences that are not necessarily accessible to validation through the senses" (p. 33). Oiler (1982) suggests that the test of validity relates to whether the "findings are recognized to be true by those who had the experience" (p. 181). Hinds, Scandrett-Hibden, & McAulay (1990) suggest that reliability and validity could benefit by evaluating the relevance of the study. "Relevance is determined by the accuracy of the research findings as perceived by those who are knowledgeable about the phenomena being studied" (p.413). The validity and reliability of this qualitative study was maintained by the following strategies:

1. The researcher believed the lived experiences as described by the informants in this study.
2. At each stage of the analysis, the researcher returned to the participants for confirmation that the researcher's interpretation of the data was correct.

Validity was maintained because the perceived "truth" of the experience was confirmed by the participant.

3. Experienced qualitative researchers and those knowledgeable about children with ADHD reviewed the data analysis.

Validity and reliability can be important issues when conducting qualitative research, especially when small sample populations are used to explore the experience of a phenomenon, but the combination of participant validation and inter-rater validation that



enable the reader to judge for themselves the validity of the study. Giorgi (1975) discussing validity in qualitative research noted that the “chief point to be remembered with this type of research is that. it is not so much whether another position with respect to the data could be adopted... but whether a reader, adopting the same viewpoint as articulated by the researcher, can also see what this researcher saw” (p. 96).

## CHAPTER IV

### RESULTS/DATA ANALYSIS

As the data were analyzed, four focal meanings emerged from the parents' descriptions of the experience of living with a child that has ADHD. Identified themes in each focal meaning are included, followed by samples of the parents' actual descriptions. . Synthesized meanings and themes without the parents' descriptions are then presented, followed by the structural description of the experience at the end of this chapter. This format was included to assist the reader in seeing the meaning of the parents' experience of living with a child that has ADHD as described in this study.

#### Focal Meaning One

##### Discovery

##### Theme One: Early realization of a problem

- He was the only one out of our four children that would go in the cupboards and pull pots and pans out and that kind of stuff
- I would watch him interact with the kids and play with the other kids. And you could see the kids at one level here and you would see my son just a step above; boink, boink, boink, two seconds here, two seconds there.

- She had a problem thinking or communicating, or whatever. She couldn't communicate. When she couldn't get it across what she wanted, she would often tug at you or fight at you.
- She was real impulsive. She never thought about what she was gonna do or how she was gonna do it, she just knew she had to do it. She had five black eyes, and five stitches, and a broken wrist before she was five years old, because she didn't think about anything.
- He never had a problem with keeping himself busy.
- He was a totally different child. I described it as being lost in space.

#### Theme Two: Beginnings of school

- If you watched him, you could just pick up that he was always a little more active than the rest of the kids.
- The second report card came along and it looked just like the first one...there was no improvement, which kind of sent red flags up to me saying this kid might have a problem.
- I had a problem with her talking....she first went to like a daycare setting...and they in turn (the people who worked in that setting) thought she was fighting...they did not want her there no more.
- The first time I noticed that there might be a problem with her was in kindergarten. Her kindergarten teacher couldn't decide if she should keep her

another year or if she should send her on and let the first grade teacher decide if it was a learning thing or what.

- The teacher said ... it was like re-teaching her all over again everytime they had to do something.
- He went on to kindergarten where we decided something was wrong. We were not sure what it was. He wouldn't know half of the things I knew he knew.
- He was tested by the psychologist and I said there was something here that the psychologist just wasn't picking up.

#### Theme Three: Diagnosis

- I think he was probably ADHD then, when he was, you know, a little guy...by the time we got into the doctor he had lost a whole year of school.
- I had to get her examined and see what the problem was. They found out she was LD and ADHD... I didn't really find out what she was until she went and seen the doctor.
- She was like a classic example of hyperness.
- We decided to have him tested for Attention Deficit Disorder and that's what the problem was.

#### Theme Four: Ongoing realizations

- He's a loner and that's pretty typical of ADHD kids.
- He doesn't have an interest once he figures something out.

- Sometimes she has to do them 1,2,or 3 times over because that is the way these kids are.
- With these kids anytime they are off track you've got to be right there and put them back on track.
- It is like 3 TV's on, but there is only 1.
- They can't stop, and go, okay is this right or is it wrong, you know. That's what they're supposed to do, but it's not always easy for them to do that and make the right choices and the right thing.
- Living with a child with ADHD is like a constant reminder, you constantly have to reinforce.

#### Focal Meaning Two

#### Searching for Control

#### Theme One: Managing the medication

- It wasn't working for him anymore, we decided maybe we should up the dose higher and that didn't seem to help, so we changed the medication to a different one.
- To me once the teachers realized that she was taking it, it's as if they wanted more, more, more, you know. Here is this kid, as if this is a wonder drug and this medicine is supposed to make them behave right then.
- I have had a lot of people down me as a parent for giving him ritalin, saying that they felt there were easier ways to treat those kids.

- If you give the Ritalin too late he can't sleep...If you give him too much medication it can have a reverse effect, then he gets more agitated, more defiant, and more manipulative.
- Her last pill was at 3:00 p.m. and it'd worn off and she had to somehow socialize with these kids and there were problems.
- Once she started taking the medication she became a whiner.
- Once she started taking the medication it was like a night and day difference.
- She did need the medication, because she needed something to help her sleep.

#### Theme Two: Managing in school

- I have met some teachers that were very, they were good in what they do, and knew how to work with children; they had patience as opposed to others, I found that it helped once I kept the communication open with these different people.
- In every grade she has had an aide that has helped her with everything.
- I try to meet with the teachers at the beginning of the school year, introduce myself and let them know I am working with them.
- I always kept in contact with the teachers to make sure everything was on target and stuff like that.
- I told the principal that until we had his medication straightened out I didn't want to bring him to school.

- He does have extra help at school for the homework and we had a big talk about this at conferences.

#### Theme Three: Managing the child

- It is constantly reminding him of something that he needs to do, being on his back all the time about something.
- It's very frustrating to figure out how to discipline this kid.
- We've tried a lot of different behavior programs.
- I still have to work with her giving me time for myself, because she will interrupt.
- I just want to instill in her that nothing is easy in life.
- It's just getting her interested in something to make her want to excel in those things or whatever.

#### Focal Meaning Three

#### Struggling for Normalization/Overcoming Obstacles

#### Theme One: School

- He was going to school, falling under the tables, on top of the tables, making noises...I didn't want the other children to think he was really a strange child.
- She would come home and would cry because the other kids in class were able to read and she wasn't able to read like they were.
- His teacher told us at that time that he was going to flunk kindergarten...how could she tell in November? She wasn't really giving him a chance

- They wanted to categorize her and put her in special ed, and I would not allow them to do that.
- Do not let them label your child.

#### Theme Two: Child

- She had a problem with ritalin; going to the pill line at school...I would tell her; you take your ritalin to help you concentrate and what's wrong with that.
- There's the point where when they realize that they are hyper and they can control themselves.
- It's the decisions that he is making right now that is so frustrating and he's not making good decisions for himself.
- What we try to teach him is...with privileges comes responsibility.
- You have to pick your battles. Is this a battle worth fighting?
- She has a real hard time...frustration is always at a high, she doesn't deal well with things that don't go her way.
- He does not like it when things don't go his way...He pouts.
- Anything he chooses to do in life I think it's going to be a struggle for him.

#### Theme Three: Self

- When I first told my husband about ADHD and what she had, he didn't believe that. He thought it was just me and I didn't want to do the mothering thing.
- It's a constant struggle always, always with her, every single day.



- I am not the most patient person and she gets on my nerves, and I know I yell at her and stuff.
- I used to just cry and like “oh why me?” I blamed being pregnant and working in a prison.
- Life has been difficult with an ADHD kid. It’s very difficult. They’re all screaming and fighting. I oftentimes have to go in and buffer those situations.
- I used to feel like such a mean mom, but it was the only way.
- You feel like you are constantly on them all the time, nag-nag-nag. That can be sometimes a terrible feeling.
- Maybe I’m being too tough as a mom.

#### Focal Meaning Four

#### Hope

#### Theme One: Mother’s Love

- The kid is amazing. He’s definitely got some brains up there.
- He’s a very sensitive little boy.
- She’s a good problem solver.
- She’s not like a brilliant child, but she’s smart, she really is very smart.
- He knows to respect adults.
- We’ll sit down together in a chair and sit and play with his hair, his ears; these things I used to do when he was a baby; he loves it still.
- She sees the good out of people.

- She has a brain...She can remember people, their faces, and stuff like that.
- She is going to be a pretty girl.
- He's a smart kid.
- He is a good-looking kid.

#### Theme Two: Focusing toward the Future

- I think if you have an ADHD child and they put you through all this stress and you still love him no matter what, you've got unconditional love.
- I think he'll take care of me when I'm old and gray.
- I realized that there were other children out there like her and it is not really a reason why, it's just that it is the way it is, and you've got to do what you can do to help.
- I don't need to justify what I feel to her because I figure that some day when she grows up and has kids of her own, she'll know that I loved her no matter what.
- It all stems from how parents are going to react, how parents are going to be supportive, if the child in this situation doesn't have the support of the family member, they just, they get out of control when they don't.
- Maybe I'll be a better person when it is all over with.

#### Summary of Meanings and Themes:

##### 1. Discovery

##### a. Early Realization of a Problem

- b. Beginnings of School
- c. Diagnosis
- d. Ongoing Realizations
- 2. Searching for Control
  - a. Managing the Medication
  - b. Managing the School
  - c. Managing the Child
- 3. Struggling for Normalization/Overcoming Obstacles
  - a. School
  - b. Child
  - c. Self
- 4. Hope
  - a. Mother's Love
  - b. Focus toward the Future

#### Descriptive Structure of the Meaning of the Experience

Living with a child that has ADHD was portrayed as a very emotional experience in this study. Based on the parents' descriptions, they all went through stages of discovering differences in their child, searching for ways to maintain control, struggling to normalize their lives and overcome obstacles, and finding hope for their child and the future. Through participant validation, several parents noted that these stages were "like an emotional roller coaster ride, only cyclic and ongoing in nature".

In addition to the impact it has on the children, “significant problems for the families have also been reported in the areas of parental perceptions, parenting competence, parent-child interaction, and general family atmosphere” (Lewis, 1992, p.372). The value in this study, the lived experience of a parent with a child with ADHD, therefore lies in the perceptions of those parents. These perceptions might have varied in type and intensity from family to family, but they all experienced periodic crises, ongoing trials, and lifelong worries that were unique to their lived experience. From these perceptions the four focal meanings emerged. Each parent who participated in this study provided descriptive elements related to the identified focal meanings.

**Discovery:** Parents in the study identified early suspicions of behavioral problems with their child. They further spoke of the emotional turmoil they experienced as their child began having problems in school and as they pursued the diagnosis to get their child the help that he/she needed. They also reported that they continue to discover different aspects of life with an ADHD child. All participants discussed the impact of discovering that their child was different and how it had affected their lives.

**Searching for Control:** After the shock of discovery, all participants spoke of the many attempts at obtaining and maintaining control in their lives. Each expressed the difficulties in searching for the right medication to make their child all better, for ways the schools could better help their child, and for ways to better control or discipline their child to make them better.

**Struggling for Normalization/Overcoming Obstacles:** To each of the parents, day to day life was seen as a struggle to maintain normalcy. Each had to deal with feelings of

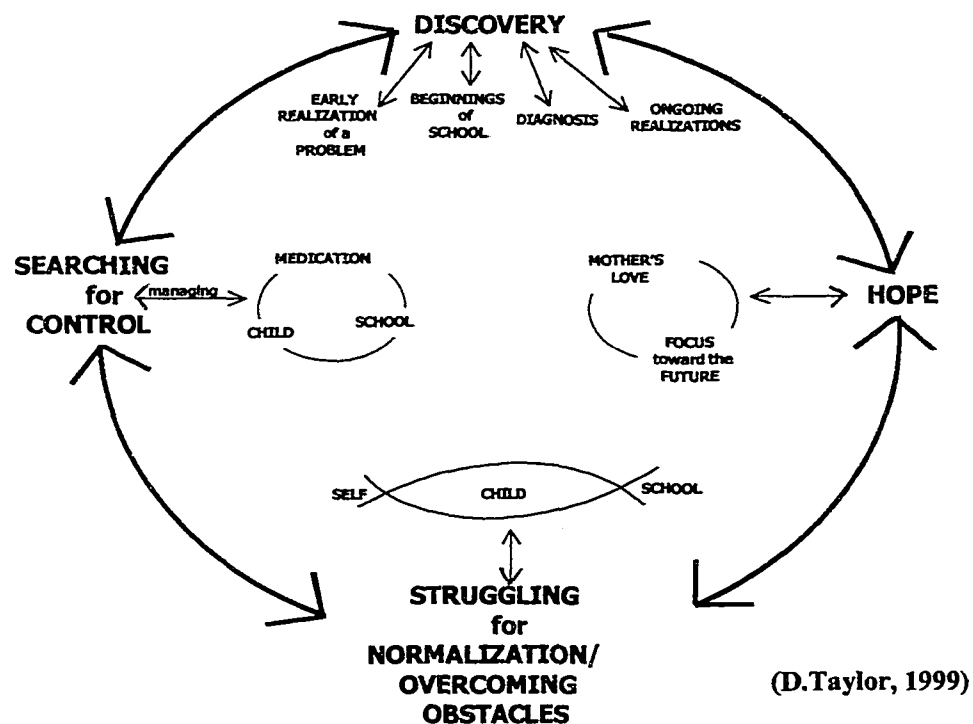
sadness concerning their child's ongoing difficulties at home and school, anger and guilt toward peoples' ignorance in relation to their child's illness, and frustration felt in overcoming these obstacles.

Hope: Although throughout this study the parents spoke of the frustration and emotional turmoil caused by their child's illness, they still expressed pride and admiration in their child's qualities. They were also able to describe some sort of acceptance of their life and a hope toward the future.

The following model was devised based on the parents' descriptions of their lived experiences and included the four focal meanings and themes of discovery, search for control, struggle for normalization, and hope.

Figure 1.

#### CYCLIC and ONGOING LIVED EXPERIENCE MODEL



## CHAPTER V

### DISCUSSION AND IMPLICATIONS

#### Discussion

Many causes of ADHD have been proposed, but essentially the exact etiology is still unknown. One fact is known; it is a chronic health condition that has an impact on every aspect of life, and an impact that continues into adulthood for affected children. Jackson (1996), citing Jessop & Stein (1988), states, "A chronic health condition has been defined as one that is long term and is either not curable or has residual features that result in limitations in daily living requiring special assistance or adaptation in function"(p. 3). The diagnosis of a chronic condition in a child produces an emotional reaction much like that of an individual experiencing grief following the death of a loved one (Johnston & Marder, 1994). The difference is the persistence of the effect on the parent[s] of the child who will require more care and attention for an indefinite period of time. As was seen in this study, these parents experienced and will continue to experience a whirlwind of emotions—from frustration, guilt, and anger to pride and joy.

Olshansky (1962) uses the term chronic sorrow to describe this persistent effect. Jackson (1974), who also uses the term chronic sorrow, notes that parents experiencing chronic sorrow "are not necessarily immobilized or prohibited from carrying on their daily

activities and from receiving some satisfaction and joy from their child. Unlike acute grief, which is intense and limited in time, chronic grief is prolonged and recurrent” (p. 1289).

According to Copley & Bodensteiner (1987), “expressions of parental grief include symptoms of anxiety, anger, guilt, and depression” (p. 69). Kubler-Ross (1976) states that “the process of grief always includes some qualities of anger” (p. 4). Therefore it can be assumed that grief can take on a variety of forms and is, in fact, a combination of different emotions.

### Findings

In this study, analysis of the parents’ perceptions of the lived experience with an ADHD child was defined as an emotional experience that progressed in stages that were cyclic and ongoing in nature. These stages of discovery, searching for control, struggling for normalization/overcoming obstacles, and hope could be compared to the stages of chronic sorrow as described by various authors. Studies by Clubb (1991), Copley & Bodensteiner (1987), Wikler, Wasow, & Hatfield (1981), and Young (1977) described parental reactions to their chronically ill children as a progression through a sequence of stages, which they defined as chronic sorrow. The findings in these studies suggested that this phenomenon of chronic sorrow is a normal reaction to an abnormal situation. The authors characterized several models of chronic sorrow as having periodic, recurring stages of impact, denial, grief, and a phase of focusing outward or restitution. These stages are similar to the emotional experience as defined in this study.

Parents in this study expressed (at times) feelings of guilt, anger, and sadness at having a child with ADHD. One parent noted she used to just cry and ask herself, “why

me”? Another wondered how she got so lucky. Most, either blamed themselves for something that they did or they felt the children had inherited the condition from someone in the family. All of the parents in the study had experienced anger at the school, at the children, at the physicians, at their family, and at themselves. Yet, despite all these negative feelings that could create a vicious cycle, they all felt that there was a positive side to it all that could help them to break free of that cycle. As one parent stated, “It all stems from how parents are going to react”. Another parent noted, “It is not really a reason why, it’s just that it is the way it is”. Furthermore, the parents felt that there could be many emotional crises in their life with the child that could send them back into the cycle. According to Copley & Bodensteiner (1987), “Many parents never move beyond the first phase of chronic sorrow” (p. 69). Living with a child that has ADHD can be a never ending; stressful experience and the effect on the parent may be either constructive or destructive. Most parents can deal with the problems they face without any detrimental effects, but as Young (1977) notes, “The parents’ degree of psychological vulnerability is reflected in their individual resistance to stress and crisis, their repertoire of coping strategies, and their personality characteristics” (p. 39).

### Literature Review

The literature review in phenomenological research is conducted after the data are collected and analyzed. The purpose of the literature review is to compare the findings from the present study to those found in the literature. While studies exist which deal with chronic sorrow as it applies to parents of children with terminal illnesses and special needs



such as, mental illness, cerebral palsy, and mental retardation, there is none known to date in regards to parents and ADHD.

Over the past few years much attention has been focused on the disorder of ADHD. A vast amount of literature has been dedicated to the diagnostic means and medical treatments recommended for use with ADHD. Since the diagnosis was formally defined in the Diagnostic and Statistical Manual of Mental Disorders, 3rd ed. (DSM III), many authors have tried to explain, analyze, and resolve the problems associated with ADHD children, but very little describes the effect it has on the parent of an ADHD child. A literature review related to the lived experience of a parent with a child with ADHD and chronic sorrow is presented and discussed in regards to the findings in this study.

#### Discovery

No parent is ever quite prepared to cope with the multitude of problems that will confront them when their child is diagnosed with ADHD. They are often labeled as troublemakers or difficult children with behavioral problems, which can result in excessive discipline or child abuse. The parents in this study began noticing early on that their child behaved differently than other children and soon realized the problems these differences caused. Parents are often judged as failures for letting their child run wild (Thomas & Chess, 1977) and parents often blame themselves for their child's behavior, wondering where they went wrong. At the moment the parent begins to suspect their child is different, followed by the actual diagnosis of ADHD, they begin to realize the impact the condition will have on their lives. One parent later commented that her child's diagnosis "was an event that marked us". Clubb (1977) notes that, "Impact signifies the beginning of

a crisis for the parents” (p. 481) and “the reality of the child’s condition poses an overwhelming threat to the parent’s life goals and feelings of self worth” (Copley & Bodensteiner, 1987, p. 69).

### Searching for Control

Johnston & Marder (1994) state that “Denial is a typical first response to the diagnosis of a child with a chronic condition. It is the mind’s natural protection against upsetting information” (p. 612). The authors, Copley & Bodensteiner (1987) state that “denial may be manifested in a variety of responses, including disbelief, not hearing, wishful thinking, shopping for cures, imaginary explanations, or distorted expectations” (p. 69). During the interview process, all of the parents discussed the multitude of medications they had experimented with before finding the “right” one for their child. Many parents when confronted with the diagnosis will search for answers to the many questions they will have, about the condition, about the medication, about how to best discipline their child, and perhaps even about how to shop around for the best physician to help them through this journey into the unknown. Clubb (1977) states that “parents engage in denial behavior because it provides them with time to face the reality of their situation gradually” (p. 462).

### Struggling for Normalization/Overcoming Obstacles

Grief is a feeling that most parents will experience when confronted with a diagnosis of a chronic condition, and parents of children with ADHD are no exception. These parents suffer a great many losses when their child is diagnosed. As the parents struggle to maintain a sense of normalcy in their lives, they may experience feelings of

anger, frustration, and guilt in regards to the cruel blow that has been dealt them. They struggle to educate others as they educate themselves about the condition. According to Clubb (1991), "grief is manifested through feelings of anger, guilt, and sadness...and may result in blaming others" (p. 462).

Anger is a feeling that many parents express when something happens to their child, "unfortunately, when it comes to a chronic illness or chronic condition, it is simply not a matter of defending the child against a predator, so the anger may be displaced in a variety of ways" (Johnston & Marder, 1994, p.613). Focusing this energy toward something constructive, such as helping their child or themselves overcome certain obstacles, helps them relieve some of this emotion. As one parent commented, "It's just that it is the way it is, and you've got to do what you can do to help....It is taking one day at a time and solving each problem as it comes along".

### Hope

The literature, in regards to this stage of the parents' lived experience, describes this as focusing outward. Clubb (1991) describes this stage "during which parents demonstrate coping measures appropriate for their situation" (p. 462) and Copley & Bodensteiner (1987) suggests that "in this stage, parents begin to successfully integrate the child and the disability into their lives" (p. 69). Parents in this study experienced joy and admiration when their child succeeded; and frustration, disappointment, and even guilt when their child failed, yet they were all able to express some hope for the future for their child and themselves. They were also able to identify with others with similar problems and offer them comfort and support. One parent commented later, that her philosophy was

that, “laughter is the best medicine and there’s a lot of funny stuff in our lives with our kids, we should enjoy it while it’s there”.

### Contrasts to the Literature

There are a number of research studies in the literature regarding parental response to their chronically ill child. In an article by Clubb (1991), three major approaches are identified. One view is the time-bound model, which contends that parental reaction progresses through a sequence of stages labeled impact, denial, grief, focusing attention, and closure. It is a linear model and is one of adaptation that implies acceptance of the child’s condition.

The second approach, chronic sorrow, suggests a different conclusion, “In Olshansky’s view, chronic sorrow is an emotional response which is manifested throughout the lifespan of the parent-child interaction. Olshansky disagrees with professionals who adopt the closure stage...[he] believes parents never achieve and proposes that parents never completely recover from the impact stage” (Clubb, 1991, p. 462).

The third approach was developed by Copley & Bodensteiner (1987) which suggests an integrated model, which has characteristics of the chronic sorrow concept, and the time-bound model. Divided into two phases, they proposed that these parents moved in a circular movement of impact, denial, and grief, labeled phase I. They further proposed that parents who were able to break out of the cycle in phase I entered into phase II, characterized by focusing outward and closure, where they were able to accept the child for who the child is, and find happiness in that.

According to Teel (1991), the key difference between the time-bound model and the chronic sorrow model is the function of the stage of denial. The author notes that in a study by Solnit & Stark (1961), “denial functions to protect the mother from depression that would otherwise occur if the child’s deficits were acknowledged” (p. 1315). It was further noted that “denial of the child’s deficits is not a component of Olshansky’s formulation of chronic sorrow...On the contrary...parents are more likely to deny the experience of chronic sorrow than to deny the recognition of the child’s disabilities” (p. 1315). The author contends that “it is this more acutely recognized deficit rather than the denial of the deficit that serves to precipitate an episode of sorrow” (p. 1315) and that Copley & Bodensteiner’s (1987) inclusion of the function of denial will only confuse further validation of the concept.

#### Participant’s Description and the Current Literature

The present study agreed with the literature findings that the lived experience was one of impact, denial, grief, and focusing outward, but disagreed with the function of closure. The participants found this experience to be one of acceptance and adjustment, but with a realization that at any given moment they could be back to the beginning of discovery and impact. This was particularly evident at certain milestones in their child’s life. Because this chronic condition is not an illness that is life-threatening and there is no known cure, parents did not see this as ever having a closure. All the participants felt that at times their lives revolved around that child and noted that a child with ADHD is a forever thing; it never goes away, but hopefully gets better with time

## Conclusions

For the participants in this study, the impact of life with a child with ADHD was an emotional experience wrought with many ups and downs, challenges, and was cyclic and ongoing in nature. The term, chronic sorrow, was introduced into the literature by Simon Olshansky in 1962 to describe a phenomenon experienced by parents of severely retarded children. He defined it as a natural, nonneurotic, understandable reaction to a tragic fact that remains constant throughout the child's life. He further noted that the intensity of the sorrow varied, between parents and families, among situations, from time to time, and could be affected by factors such as a person's personality, ethnic group, religion, and social class.

Copley & Bodensteiner (1987) took that definition further by integrating its concept with the time-bound model, proposing that chronic sorrow was divided into two phases with stages moving in a circular fashion. They further proposed that parents could become stuck in phase I; "Disability is never clear-cut as death...not knowing what fate to mourn, the parent faces a thousand alternative scenarios" (p. 69), or they could break out of the cycle and enter phase II and focus outward and find some closure.

The data presented and analyzed in this study suggests that chronic sorrow as it has been defined by Copley & Bodensteiner is a plausible emotional phenomenon in parents living with a child with ADHD.

## Recommendations and Implications

The findings from this study have several implications and recommendations for clinical practitioners. Professionals who work with parents and children with ADHD can

use the findings from this study to plan and implement strategies to help them. "If the worker accepts the validity of the concept of chronic sorrow, his goal in counseling the parent will be to increase his comfortableness in living with and managing his defective child" (Olshansky, 1962, p. 193). Early intervention strategies could prevent negative outcomes and strengthen their resources for dealing with future, stressful events.

Parenting of the child with ADHD may require skill and knowledge above that required for parenting the normal child in order to express value and comfort in parenting. A multi-modal treatment approach that includes appropriate educational programs, counseling, and medication may be important for effective parenting. "The goal is to help the parents move toward a response that will allow them to function and cope with their situation" (Young, 1977, p. 42).

Parents can benefit from sharing with other parents in similar situations. Practitioners need to provide information concerning community resources, such as support groups, so that parents can call on them when needed. Knowing that there is someone willing to listen can be extremely helpful. Practitioners "who are knowledgeable, accepting, and validating of parents' emotional responses may also facilitate the parents' adjustment" (Johnston & Marder, 1994, p. 611) with their child.

If practitioners are to understand that chronic sorrow is a normal reaction to an abnormal situation, "it entails allowing for periodic grieving and perceiving that as a strength in coping" (Wikler et al, 1981, p. 69). Further education is needed to help practitioners identify the characteristics of chronic sorrow and to use this knowledge to enhance positive coping outcomes. An understanding of the phenomenon will facilitate

support for these parents and education for others. Also, development of new sources of knowledge to address the needs of the parent, their ADHD child, and their families is an area that may involve a collaboration of various clinical and administrative specialists.

#### Recommendations for Further Research

The majority of the research in regards to ADHD has been directed toward diagnostic means and medical treatments; however there is some literature of value concerning family functioning and chronic illness. There is also research in the arena of chronic sorrow, but the bulk of this has focused on parents of children with mental disabilities or seriously chronically ill children. There is no known literature to date that explores the chronic sorrow experienced by a parent with an ADHD child.

In this study, all of the children of the participants were of the same age, pre adolescent. Replication and comparing the results of this study with various age groups of this population such as, early school-age, adolescence, and at the time children are leaving the nest, would be of value to determine if the emotional experiences expressed changed over periods of time. This would help to validate chronic sorrow as a phenomenon. The participants in this study were all mothers. Another study involving fathers may give a different perspective of the lived experience or further validate the phenomenon. Another avenue that could be explored would be to use parents who also had symptoms of ADHD. Teel (1991) suggests, "Development of an instrument to quantify the components of chronic sorrow may assist in the identification of additional populations in whom the phenomenon may occur. Analysis of the concept of chronic sorrow provides a first step in these endeavours" (p. 1317).



## Summary

This study has described and analyzed the lived experience of four parents that have a child with attention deficit hyperactivity disorder (ADHD). It represents a beginning understanding of what parents experience as they go through life with a child with this chronic condition. It also explored the concept of chronic sorrow and its relationship to these parents. Each parent described their experience as cyclic and ongoing in nature, but felt they were able to cope adequately enough to focus outward to the future. As one parent commented later, "to be the mother of an ADHD child is stressful enough, but to prevail as a mother of an ADHD child, hold onto a career, raise other children, and survive a marriage is the true test of success".

## APPENDIX A

## Telephone Script

My name is Deborah Taylor. I am a registered nurse and a graduate student at Grand Valley State University. I was told by \_\_\_\_\_ that it was all right to contact you about your possibly participating in a research study that I am conducting.

The purpose of this study is to examine the experience of living with a child that has ADHD. I hope this study will help gain a better understanding to enable nurses to provide healthcare in a manner, which will be responsive to the needs of families with an ADHD child.

If you agree to participate, I will:

1. Interview you alone in a mutually agreed upon place. If childcare needs to be provided I will pay the expense.
2. Ask you to fully describe to the best of your ability, your experience living with a child that has ADHD. This interview will probably last no longer than two hours.
3. I will tape-record the interview so I can be accurate about what you have said.
4. The tape recording will be transcribed and the tape will be destroyed once the study is completed.
5. Your identity will be protected and not revealed in any way.

This is voluntary and you may withdraw at anytime with no ill effect on your child's treatment or any provision of service. Do you have any questions?

Would you be willing to participate?

What is a good time for you?

Directions.

## APPENDIX B



1 CAMPUS DRIVE • ALLENDALE, MICHIGAN 49401-9403 • 616/895-6611

February 10, 1999

Deborah Taylor  
1240 Woodhaven  
N. Muskegon, MI 49445-2556

Dear Deborah:

The Human Research Review Committee of Grand Valley State University is charged to examine proposals with respect to protection of human subjects. The Committee has considered your proposal, "***Impact of Attention Deficit Hyperactivity Disorder on Parents and Children: What Are the Lived Experiences of a Parent with a Child with ADHD?***", and is satisfied that you have complied with the intent of the regulations published in the Federal Register 46 (16) 8386-8392, January 26, 1981.

Sincerely,

Paul Huizenga, Chair  
Human Research Review Committee

## APPENDIX C

## CONSENT FORM

I understand that this is a study of the lived experiences of a parent with a child with Attention Deficit Hyperactivity Disorder (ADHD) and that knowledge gained is expected to help nurses provide healthcare in a manner which will be responsive to the needs of families with an ADHD child.

I also understand that:

1. participation in this study will involve a tape recorded interview approximately 2 hours in length, regarding my feelings, thoughts, and perceptions of what it is like to live with a child with ADHD.
2. that I have been selected for participation because I have a child diagnosed with ADHD.
3. it is not anticipated that this study will lead to any physical or emotional risk to myself and it may be helpful just to talk to someone about my experience.
4. the information I provide will be kept strictly confidential and the data will be coded so that identification of individual participants will not be possible.
5. that the tapes will be destroyed once the study is completed.
6. a summary of the results will be made to available to me upon request.

I acknowledge that:

I have been given the opportunity to ask questions regarding this research study, and that these questions have been answered to my satisfaction.

In giving my consent, I understand that my participation in this study is voluntary and that I may withdraw at any time with no effect on my child's treatment or any provision of service.

I hereby authorize the investigator to release information obtained in this study to scientific literature. I understand that I will not be identified by name.

I have been given the telephone numbers of the researcher, the thesis committee chairperson, and the chairperson of the Grand Valley State University Human Research Review Committee. I may contact them at any time if I have questions concerning this study or consent form, including questions about the research or my rights as a research subject.



I acknowledge that I have read and understood the above information, and that I agree to participate in this study.

\_\_\_\_\_  
Witness

\_\_\_\_\_  
Participant's Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Date

\_\_\_\_\_ I am interested in receiving a summary of the study results.

**You will be given a copy of this consent form to keep.**

Deborah Taylor, BSN, RNC (616) 744-3375  
**Researcher**

Dr. Lorraine Rodrigues-Fisher (616) 895-3558  
**Thesis Committee Chairperson**

Dr. Paul Huizenga (616) 895-2472  
**Chair of Grand Valley State University  
Human Research Review Committee**

## LIST OF REFERENCES

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American Psychiatric Association (1987). Diagnostic and Statistical Manual of Mental Disorders, 4rd ed. (DSM III). Author: Washington, D. C.

Barkley, R. (1990). Attention-deficit hyperactivity disorder: A handbook for diagnosis and treatment. New York: Guilford Press.

Buncher, P. (1996). Attention-deficit hyperactivity disorder: A diagnosis for the '90s. Nurse Practitioner, 21, 43-65.

Clubb, R. (1991). Chronic sorrow: adaptation patterns of parents with chronically ill children. Pediatric Nursing, 17, 461-466.

Copley, M. & Bodensteiner, J. (1987). Chronic sorrow in families of disabled children. Journal of Child Neurology, 2, 67-70.

Dzurec, L. & Abraham, I. (1986). Analogy between phenomenology and multivariate statistical analysis. In P. L. Chinn (Ed.), Nursing Research Methodology, (pp. 55-66). Rockville: Aspen Publishers, Inc..

Giorgi, A. (1975). An application of phenomenological method in psychology. In A. Giorgi, C. Fisher, & E. Murray (Eds.), Duquesne studies in phenomenological psychology, (Vol. 2, pp. 82-103). New Jersey: Humanities Press.

Hinds, P., Scandrett-Hibden, S., & McAulay, L. (1990). Further assessment of a method to estimate reliability and validity of qualitative research findings. Journal of Advanced Nursing, 15, 430-435.

Jackson, P. (1974). Chronic grief. American Journal of Nursing, 74, 1288-1291.

Jackson, P. (1996). The primary care provider and children with chronic conditions. In P. Jackson & J. Vessey (Eds.), Primary care of the child with a chronic condition (2nd ed., pp. 3-15). St. Louis: Mosby-Year Book, Inc..

Jasper, M. (1994). Issues in phenomenology for researchers of nursing. Journal of Advanced Nursing, 19, 309-314.

Johnston, C. & Marder, L. (1994). Parenting the child with a chronic condition: an emotional experience. Pediatric Nursing, 20, 611-614.

Koch, T. (1995). Interpretive approaches in nursing research: the influence of Husserl and Heidegger. Journal of Advanced Nursing, 21, 827-836.

Kubler-Ross, E. (1993). On death and dying. New York: Collier Books.

Lewis, K (1992). Family functioning as perceived by parents of boys with attention deficit disorder. Issues in Mental Health Nursing, 13, 369-386.

Morse, J. (1989). Strategies for sampling. In Morse, J. (Ed.), Nursing research: A contemporary dialogue, (pp. 118-131). Rockville: Aspen Publishers, Inc..

Munhall, P. & Oiler, C. (1986). Nursing research: A qualitative perspective. Norwalk: Appleton-Century-Crofts.

Oiler, C. (1982). The phenomenological approach in nursing research. Nursing Research, 31, 178-181.

Olshansky, S. (1962). Chronic sorrow: a response to having a mentally defective child. Social Casework, 43, 190-193.

Omery, A. (1983). Phenomenology: a method for nursing research. Advances in Nursing Science, 5 (2), 49-63.

Parse, R., Coyne, A., & Smith, M. (1985). The phenomenological method. In Parse, R., Coyne, A., & Smith, M. (Eds.), Nursing research: Qualitative methods, (pp. 15-25). Bowie: Brady Communications Company.

Polit, D., & Hungler, B. (1995). Nursing research: Principles and methods (5th ed.). Philadelphia: J. B. Lippincott Company.

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

Stevens, L., Zentall, S., Deck, J., Abate, M., Watkins, B., Lipp, S., & Burgess, J. (1995). Essential fatty acid metabolism in boys with attention-deficit hyperactivity disorder. American Journal of Clinical Nutrition, 62, 761-768.

Swanson-Kauffman, K. (1986). A combined qualitative methodology for nursing research. Advances in Nursing Science, 8 (3), 58-69.

Teel, C. (1991). Chronic sorrow: analysis of the concept. Journal of Advanced Nursing, 16, 1311-1319.

Thomas, A. & Chess, S. (1977). Temperament and parent-child interaction. Temperament and development (pp. 66-81). New York: Brunner/Mazel.

Wikler, L., Wasow, M., & Hatfield, E. (1981). Chronic sorrow revisited: parent versus professional depiction of the adjustment of parents of mentally retarded children. American Journal of Orthopsychiatric, 51, 63-70.

Young, R. (1977). Chronic sorrow: parents' response to the birth of a child with a defect. The American Journal of Maternal Child Nursing, 2, 38-42.

## BIBLIOGRAPHY

## BIBLIOGRAPHY

American Psychological Association (1994). Publication manual of the American Psychological Association (4th ed.). Washington, DC: American Psychological Association.

Gill, B. (1997). Changed by a child: companion notes for parents of a child with a disability. New York: Doubleday.

Hallowell, E. & Ratey, J. (1994). Driven to distraction: reorganizing and coping with attention deficit disorder from childhood through adulthood. New York: Pantheon.

Kirkhof School of Nursing. (1997/1998). Thesis handbook. Allendale, MI: Grand Valley State University.