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The experience of families of children diagnosed with autism

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THE EXPERIENCE OF FAMILIES OF CHILDREN DIAGNOSED WITH AUTISM

A Project
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Social Work

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by
Rachel Ann Lakin
June 2009

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ABSTRACT

This study assessed the issues faced by families who have a child diagnosed with autism using the post-positivist paradigm. This research methodology allowed the researcher to gain a clear understanding of the experience of families with a child with autism and the obstacles they face. The participants were interviewed by telephone to allow them to explore their thoughts and emotions about living with a child diagnosed with autism. This study built a theory that enhances understanding of the experience of families of children with autism. The findings of this study suggested that families of children with autism who have an Applied Behavior Analysis (ABA) program have hope despite the stressors they experience associated with having a child with a disability. This may aid professionals in implementing appropriate interventions that will benefit children with autism and their families. Further, it may remind professionals of the stressors associated with having a child with autism, and the hope ABA brings to these families.

ACKNOWLEDGMENTS

I would like to thank Dr Rosemary McCaslin for all her hard work and input. I appreciate all the help and encouragement she has given me throughout this project.

I would also like to thank Center for Autism and Related Disorders for allowing me to recruit participants from their agency in order to gain further understanding of the experiences of families of children diagnosed with autism.

DEDICATION

This project is dedicated to my boys and their families.

Erick & Andy

Hendrik

And

Zachary

You are the inspiration to my project and have taught me so much.

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CHAPTER ONE

ASSESSMENT

Introduction

This chapter discusses the focus of the research which was to explore the experience of families of children diagnosed with autism. In addition, this chapter includes the methodology used in this research project and explains the reasoning behind choosing this paradigm. A review of the literature is also included in this chapter to give a background and theoretical framework for the current study. Finally, the potential contribution to micro and macro social work practice is addressed in this chapter.

Research Focus

This study sought to understand the needs of the families who have a child diagnosed with autism. This was to gain insight into what services and interventions are needed to help children with autism and their families. Services and interventions aimed at reducing familial issues related to having a child with autism allows them to meet their needs on a physical, mental, emotional, and spiritual level.

This study is important because it aids families of children with autism to have their needs met. Further, the incidence of autism is increasing and therefore it was important to understand the needs of families of children with autism. Additionally, qualitative research assessing the needs and struggles of families of children with autism is limited and needed to be furthered in order to enhance the services provided to children with autism and their families. Finally, a deeper understanding of families will allow appropriate interventions aimed at helping children with autism and their families.

The study explored familial relations including marital issues, parenting styles, financial issues, and perceived stress for both parents and siblings. The researcher also explored service needs. Additionally, it addressed the experience of families in maintaining an intensive Applied Behavior Analysis (ABA) program in their home.

Paradigm and Rationale for Chosen Paradigm

The post-positivist paradigm was used to gather data on the study participants. The post-positivist paradigm was utilized to develop a theory based on the narrative interviews with participants. This methodology allowed the study to enrich the understanding of a specific area of interest and alter specific questions in the interviews when an emerging theme is noticed by the researcher.

This paradigm was chosen to develop a deeper understanding of the struggles families who have a child diagnosed with autism endure. This paradigm allowed the study to fully assess the experience of families of children diagnosed with autism, which aided in gaining a more extensive understanding of their struggles. In addition, this paradigm allowed the participants to express, in their own words, how having a child with autism has affected their lives.

This approach did not confine the participants to criteria measured on a survey. This was important because it allowed the researcher to gain clarification on any questions asked when needed. This methodology also allowed the participants to ask the researcher any questions about issues they faced with having a child diagnosed with autism. This was beneficial since the researcher had experience working with this population.

Finally, there was a need to develop a further understanding of the needs of families who have a child diagnosed with autism. An understanding of the experience of families of children diagnosed with autism may help agencies to develop the most appropriate intervention that will meet the needs of the families of children diagnosed with autism.

Literature Review

Review of Research

This section explored the research on families of children diagnosed with autism. Specifically, this section included issues related to parents and siblings of children diagnosed with autism, as well as issues that arise for the family as whole in living with a child with autism. The purpose of this section was to review the literature and gain a deeper understanding of the issues faced by families of children diagnosed with autism.

Theories Guiding Conceptualization

The guiding theory of this research project was Family Systems theory. This theory asserts that family systems are intertwined with other systems, which is demonstrated in this project within the ABA program and how an ABA program can influence the family as a whole. In addition, the experience of one member in a family or the rise of a disability causes changes in the family system. Subsystems, including sibling-sibling, parent-parent, or parent-sibling relationships, are also important in family systems, pointing to how the family members interact with one another when a child with autism lives in the home. Finally, there is an emphasis on homeostasis in family systems theory, which is important to assess in families of children with autism because of the multiple changes that occur with a child diagnosed with autism (Zastrow & Kirst-Ashman, 2007).

Autism

Autism is characterized by social and language impairment. In addition, stereotypical or repetitive behavioral patterns are present in this disorder. Autism is more frequently diagnosed in males than females, and is diagnosed in two to 20 per 10,000 individuals (American Psychological Association [APA], 2000). However, studies have demonstrated that the prevalence of autism is much higher. Studies estimate autism rates to affect one in 150 children (Center for Autism and Related Disorders [CARD], 2001). Although there is no cure for autism, Center for Autism and Related Disorders (CARD) asserts that ABA therapy is able to reduce the symptomology associated with autism.

Applied Behavior Analysis Therapy

CARD describes ABA as the methodical employment of behavioral strategies to obtain a desired behavior. Further CARD utilizes a Discrete Trial Setting, to aid in the acquisition of learning appropriate skills and behaviors. A Discrete Trial Setting involves the repeated presentation of the same command (discriminative stimulus) in a ten trial setting. This allows the child to more easily learn the desired skill. An important aspect of ABA is its individualization to each child since all children with autism exhibit different behaviors and have different needs. This approach to teaching behaviors is easily measurable since behaviors are often taught in steps. Finally, an emphasis of behavioral change is the increase of appropriate behaviors and the reduction of stereotypical and inappropriate behaviors (CARD, 2001)

Parental Issues

The experience of raising children diagnosed with autism is likely extremely challenging. The degree of difficulty in raising a child with autism often makes it difficult for the parents to maintain a positive sense of their parenting skills (Kuhn & Carter, 2006). An autism diagnosis presents families with special challenges and increases depression in parents as a response to those demands (Hillman, 2006). This increase in depression may increase feelings of disappointment, rejection of the child with autism, and difficulty relating to the special needs child. These negative emotions can increase stress and therefore lead to a possible increase in abuse (Mandell, Walrath, Manreuffel, Sgro, & Pinto-Martin, 2005). This may result in feelings of inadequacy in parenting ability and fears of not doing enough to promote their child's developmental needs (Kuhn & Carter, 2006). Thus parents with a child diagnosed with autism often face hardships in effectively parenting their child diagnosed with autism and may feel that they are ineffective in their parenting skills.

According to Gray (2003), mothers and fathers of children diagnosed with autism report having a different experience from one another regarding the diagnosis. The author asserts that fathers report that the diagnosis of autism did not have a personal effect on them. This is often because they are at work and do not take on a majority of the care giving responsibility for the children. In contrast, the author argues that the mother of the child diagnosed with autism reports an increased stress level in relation to that child. The author also notes the mothers affirm that the diagnosis had a significant impact on them regardless of their work status. This indicates that the mother is often the primary caregiver and thus carries the burden of stress for caring for their child with autism (Gray, 2003).

Parents of children diagnosed with autism not only face difficulties associated with the diagnosis of autism, but also experience a great deal of stress during the diagnostic process as well. All too often, parents need to take their child to specialists several times before receiving an autism diagnosis (Siklos & Kerisk, 2007). Further, the authors suggest that parents are largely dissatisfied with the diagnostic process. Parents report that they are not informed about the services provided that will alleviate some of the stress associated with raising a child diagnosed with autism (Siklos & Kerisk, 2007).

Another stress factor for parent with a child diagnosed with autism is the stress associated with maintaining an ABA Program in their homes (Hillman, 2006). Parents report a lack of financial security due to the financial demands of an appropriate ABA program. The cost of an ABA program is extremely high, and middle income families are often unable to afford the program on their own, and can only provide an ABA program if the school district is able to fund all or part of a program. Further, the authors suggest that parents who do not understand behavioral principles are more likely to report an increase in stress. When parents do not understand behavioral strategies, they often fail to enforce behavioral interventions because it is often easier for the parent to give into the child's maladaptive behaviors (Hillman, 2006).

Further, even when parents are involved in their child's behavioral treatment, they often continue to feel that they are not advancing their child's development (Kuhn & Carter, 2006). However, when parents are trained properly in their child's diagnosis and appropriate intervention, depressive symptoms are alleviated and parents feel more competent being involved in their child's treatment (Bristol, Gallagher, & Holt, 1993). Additionally, mothers may disengage from non-disabled family members due to the burden of caring for a child diagnosed with autism (Martin & Cole, 1993).

Sibling Issues

Benderix and Sivberg (2007) report that siblings of children diagnosed with autism have a unique life experience which often is viewed as negative. Siblings often feel the need to care for their sibling diagnosed with autism and may take on a parental role with their sibling. Further, the authors suggest that siblings of children diagnosed with autism may feel embarrassment about having a sibling with a developmental disability. The authors report that the siblings often do not disclose that their sibling has autism to peers at school. Additionally, they often do not invite friends over, due to the disruptive and sometimes violent behavior exhibited by their sibling with autism. This violent behavior sometimes causes fear and feelings of not being safe in their home.

Although these siblings have many negative emotions about their sibling with autism, they still feel empathy, especially when their sibling is afraid, sad, or frustrated. In addition, the siblings of children diagnosed with autism report that they fear for their disabled sibling's future (Benderix & Sivberg, 2007). These findings indicate that a bond exists between children diagnosed with autism and their siblings despite the hardships that accompany living with a child with developmental issues.

Familial Issues

A diagnosis of autism presents families with special challenges. This diagnosis alters family life negatively and increases the difficulty of families engaging in normal activities (McDonald, Poertner, & Pierpont, 1999). Specifically, potential outbursts of maladaptive behavior from the child diagnosed with autism often prevent families from engaging in a variety of activities. These maladaptive behavioral outbursts that are associated with autism make families feel set apart from other families that do not have to deal with these challenges. This may result in families of children diagnosed with autism reporting that they feel that their family life is abnormal (Gray, 1997).

Additionally, family cohesiveness alters the way families view the diagnosis of autism and the structure of the family. The idea of family cohesion may increase with having a child diagnosed with autism because the family members must be resourceful to meet the demands that encompass caring for a child with autism (Martin & Cole, 1993). This idea of increased family cohesion suggests that these families pull together as a team in order to reduce the stress of caring for a child with autism for all family members.

Potential Contribution of Study to Micro and Macro Social Work Practice

This research is important for both micro and macro social work practitioners because it helps them to gain insight into the lives of families who have a child diagnosed with autism. Micro practitioners benefit because this study may allow them to work more effectively with clients by facilitating empathy, and allowing the micro practitioners to employ interventions aimed at relieving familial and environmental stress. Macro practitioners will be able to use the data gathered in this study to help advocate for and create policies designed to reduce the stress involved with raising a child diagnosed with autism.

Summary

This chapter addressed the focus of the research and the paradigm chosen to carry out the current study of families of children diagnosed with autism. This chapter also included a review of the literature on families of children diagnosed with autism. An exploration of the potential contribution to micro and macro social work practice was also included.

CHAPTER TWO

PLANNING

Introduction

This chapter includes a description of the study participants and how the researcher engaged the participants of the study. Also included in this chapter was an exploration of the diversity, ethical, and political issues that may have arisen during the course of the study. Further, this chapter assesses the methods for data collection, recording, and analysis. Finally, this chapter includes a plan for termination with study participants and describes how the findings of the study were communicated to the study participants and the research site.

Plan for Engagement

Research Site and Study Participants

The research participants were parents of children diagnosed with autism. The families included in the study receive behavioral intervention from the Center for Autism and Related Disorders (CARD), at the Temecula office. CARD is an agency that provides ABA therapy to children with autism by training therapists to employ behavioral interventions in the client's home. Further, CARD also provides team meetings for each client, which include a supervisor, to enhance the ABA program and ensure that all therapists on the child's case are employing the same techniques. CARD also helps educate parents on appropriate behavioral interventions, so they can employ the same strategies used by the therapists to ensure consistency for the child in the home. The 15 participants involved in the research had to have at least one neuro-typical child and a child with a diagnosis of autism in order to participate in the study.

Engagement Strategies

First, this researcher met with a supervisor at CARD to discuss the possibility of interviewing clients receiving services at their agency. Furthermore, the gatekeeper has access to CARD headquarters, and as a supervisor at the Temecula office, she was able to provide information on the study to CARD headquarters. She was also able to obtain permission from the clients to potentially be involved in the study. Additionally, the supervisor, who was the gatekeeper of this project, provided the researcher with information on the clients who were interested in participating in the study.

Once the researcher obtained the contact information for potential participants, they were contacted via email, and invited to be a part of a study on families with children with autism. Further, the email provided potential participants with contact information if they choose to be included in the study. The participants were informed that it was their choice to be involved in the study and participation in the study would not affect their services from CARD. The email also included an Informed Consent (Appendix A) to allow the participants to understand the reasoning behind the current study as well as potential risks and benefits.

Self Preparation

The researcher obtained phone numbers of the study participants and set up individual meetings with the participants in their homes. During the interview, the researcher introduced herself and discussed her reasoning for conducting research, including her experience working with children diagnosed with autism. The researcher also provided informed consent which notified the participants that the information obtained in this interview remained confidential and was only used to gather research data. Finally, the researcher informed participants that they would not be judged for any negative emotions about their child's diagnosis and other related issues.

The researcher prepared herself to be sensitive to the families of children diagnosed with autism by empathically listening to the interviewee. In addition, the researcher utilized her current knowledge of the problems related to having a child with autism, to develop an understanding of the experience of the families of children with autism. The researcher also continued to obtain new knowledge regarding the issues families of children with autism endure in order to gain a greater understanding of this population. Finally, since the researcher had previous experience working with this population, she evaluated her own biases about the experience of families of children with autism.

Diversity Issues

Issues of diversity may have included cultural issues such as ethnicity because a diagnosis of autism affects members of all cultures. Therefore the researcher remained sensitive to many cultural factors, including the potential struggles faced by families of children with autism and considers differences in culture during interviews since all cultures can be affected by autism. Further, the study remained aware of cultural issues related to late diagnosis of minority children when conducting the interview. Additionally, the researcher does not have children of her own which may have caused the participants to question her knowledge about the experience of having children with an autism diagnosis. However, the researcher has worked extensively with children diagnosed with autism as an Applied Behavior Analysis (ABA) Therapist. This likely helped the participants feel more at ease and understood by the researcher.

The specific diversity issues for this population included difficulties with traveling or having an unknown person in the home because children with autism are often resistant to new stimuli and changes in their environment. In addition, time constraints may have been a special issue in this population. Many families of children with autism seek different therapy modalities aimed at reducing symptoms related to autism, which can lead to a busy schedule. Further, ABA programs with CARD can be up to 40 hours a week for the child with autism.

Finally, there is an increased stress with members of this group. This increase in stress is due to maladaptive behaviors seen in children with autism that can sometimes frustrate or embarrass the family members.

Ethical Issues

The study remained conscious of the ethical issues that may have arisen when using the post-positivist paradigm in research. The issues included threats to confidentiality that may occur with the engagement of, and close working relationship between the study participants and the researcher. To ensure the participants' knowledge of confidentiality the researcher provided an informed consent (Appendix A) to the participants. The informed consent notified the participant of their right to privacy as well as any risks that may have arisen due to being a participant in the study.

Political Issues

The gatekeeper in the study works as a supervisor for CARD and has a close working relationship with the study participants. CARD supervisors work side by side with the family in order to provide the most appropriate intervention for the child with autism. The researcher worked with these relationships by assuring confidentiality for the study participants in regard to frustrations that may arise during the interview pertaining to CARD and the CARD supervisors, in order to allow the participants to fully express their experience with having a child with autism in an ABA program.

Plan for Implementation

Data Gathering

A face to face interview or phone interview was utilized to gather data on the experience of families of children diagnosed with autism. Each parent was interviewed separately in order to obtain perspectives of both the mother and the father of the child diagnosed with autism. In order to maintain privacy for both parents the researcher asked the parent not being interviewed to allow time for their spouse to engage in the interview process. Further, the researcher suggested that the spouse not involved in the interview engage in an activity with their children in order to allow privacy for the parent who was being interviewed.

Selection of Participants

Parents of clients receiving ABA therapy services through CARD were interviewed. A homogenous sample was utilized as the study needed to use only participants who have a child who is diagnosed with autism. A homogenous sample is described as a sample that utilizes a specific group in order to allow a concentrated study targeted at a particular group of people (Morris, 2006). This strategy allowed for a comprehensive look at the issues faced by families who have a child diagnosed with autism. This is the most appropriate approach to gathering data for this study, because the target group must have child diagnosed with autism, receive services from CARD, and have neuro-typical siblings included in order to fully understand what family members of this group experience when a child is diagnosed with autism.

The study planned to conduct interviews with 15 participants. In the event that more participants volunteered than the expected number, the study allowed for more participants to be interviewed and included their data in the results of the study.

Phases of Data Collection

Data were collected via interviews with study participants. The interview began with an explanation of the study and a brief description of the researcher's experience with autism. This was done to give the participants an understanding of the researcher's interest in autism and develop rapport with the participants. This may have made the participants feel like the researcher had a richer understanding of their experience, although the researcher's experience differed from their own.

To begin the interview, the parents were asked questions to understand the family background. This portion of the interview included questions related to number of children and their ages, marital status, socioeconomic status, and age their child was diagnosed with autism. Next, the participants were asked questions to explore the experience of having a child with autism, including affects on marriage and parenting relationships, effects of diagnosis on personal and familial life, financial concerns, stress of an in home ABA program, perception of neuro-typical sibling's stress related to having a sibling with autism, and stressors related to their experience of having a child with autism. Finally, questions were used to wrap up the interview. This time was utilized to thank the participants for being a part of the study. Topics for questions asked during the interview can be found in Appendix B.

Data Recording

The interview was recorded with audio recording after receiving permission from the participants. The audio recording allowed the information to be listened to multiple times, and therefore allow the study to develop a richer understanding of the participants. Notes were also be taken during the interview, when conducted over the phone or if a participant did not give permission to be recorded. This was done to gather information conveyed during the course of the interview. The notes taken during the interview were kept in a journal. A second journal contained the researcher's impressions, thoughts, and an organization of the themes that developed during the interview.

Plan for Evaluation

Data Analysis

The researcher used bottom up analysis to examine the data gathered from the study participants. Bottom up analysis consists of open coding, axial coding, selective coding and the conditional matrix as described by Morris (2006).

Open Coding. Open coding is the process of extracting information from the interviews by the method of micro-analysis of the narrative data. Microanalysis is the process of selecting a section of the interview and analyzing that piece in detail in order to extract the most important information and separate the ideas into categories. An example of potential open coding would be an increase in financial stress after receiving an autism diagnosis.

Axial Coding. Axial coding consists of connecting the categories that were established during open coding. This allows the researcher to make assumptions about the information and to become more focused in the research. This also allows the researcher to visually see the possible correlations with an axial code.

Selective Coding. Selective coding is described as the method used to incorporate and refine the codes in order to help build the theory. This method allows the researcher to not only develop their theory, but describe the process of building the theory.

The Conditional Matrix. The conditional matrix examines how this study's findings can be employed at the individual, familial, group, community, and national levels. This allows the researcher to connect their research to all the areas that social work practice encompasses, thus benefiting social work practice.

Plan for Termination

Communicating Findings to Study Site and Study Participants

The findings of this study were presented at the Department of Social Work's annual poster day. The participants were invited to attend. The supervisors at CARD from the Temecula office were also invited to help them gain an understanding of the experience of families who have a child diagnosed with autism.

In addition to the presentation of the project at the department of Social Work's annual poster days, the findings of the study were also presented at CARD's

Temecula office to allow participants as well as the staff at CARD to receive information on the study. Refreshments were provided during the presentation at CARD. This helps the treatment providers at CARD to implement treatment goals that will benefit the whole family.

Termination of Study

The researcher terminated the relationship with the participants when the study was completed. The relationship with CARD was also terminated once the study was completed. At the end of the study, CARD was provided with a copy of the research project to allow them to maintain the information gathered in the study.

Plan for Follow Up

Ongoing Relationship with Study Participants

The researcher did not plan to continue an ongoing relationship with the participants or gatekeeper at the study site. However, the researcher planned to continue her work with children diagnosed with autism and their families after completion of her Master of Social Work degree.

Summary

A description of the study participants and how the participants will be engaged in the research project were included in this chapter. In addition, this chapter assessed diversity, ethical, and political issues that may have arisen through the course of the research project. Methods of data collection, recording, and analysis were also explored in this chapter. Finally, this chapter included the plans for termination and follow-up with the study participants once the study was completed.

CHAPTER THREE

IMPLEMENTATION

Introduction

This chapter reviews the implementation of the research. A review of the actual participants and research site is included to provide information on the demographics of the participants. In addition, the methodology for gathering data and recording data are included in this chapter.

Research Site and Study Participants

The research site that provided information on their clients for this study was Center for Autism and Related Disorders (CARD). CARD is an agency that provides Applied Behavioral Analysis (ABA) therapy to children with autism and works with their families to help children learn appropriate behaviors. This study interviewed six families totaling 11 study participants all of whom receive ABA services from CARD. All study participants have at least one child diagnosed with autism who receives ABA services.

Selection of Participants

All participants selected for the study have at least one child who receives ABA services from CARD. However, due to the low number of participants, not all of the participants have a neuro-typical child. Specifically, five of the 11 participants did not have a neuro-typical child. Two of the five participants had two children with autism, one had only one child, and two had one child with Pervasive Development Disorder - Not otherwise Specified and one child with language delay and receiving early intervention services. The supervisor at CARD at the Temecula office provided the study with the email addresses of the potential study participants.

The email addresses of 10 potential participants were provided to the researcher. Of the 10 clients emailed, six agreed to participate in the study. The interviewer spoke with the each of the participants and asked to speak to their spouses. All but one participant's spouse was willing to participate in the interview. All participants in this study were married.

Data Gathering

Data were gathered for this study by conducting telephone interviews. The researcher chose to interview participants only via telephone due to difficulty in scheduling in home interviews with both parents. In addition, both parents were interviewed separately in order to maintain confidentiality and to gain the perspective of each parent regarding their experience of having a child with autism and its effects on personal relationships.

Phases of Data Collection

To begin date collection, the study requested the email addresses of potential participants from CARD, Temecula office. Participants were then contacted via email. The researcher introduced herself in the email and explained her interest in the topic of autism. Also included in the email was a copy of the informed consent. See appendix A. Once participants confirmed they were willing to participate in the study, verified times that they were available for interview, and provided a phone number, the researcher began calling the participants at the times indicated.

When the researcher called the participants she began by again explaining the reasoning of the project and gave a background on her interest in the diagnosis of autism. The informed consent was also read to the participants, to which they provided a verbal agreement to participate in the study. When providing the informed consent to the participants, the researcher explained that an audio recording would not be utilized for interviews over the phone because of the technical issues of setting up an audio recording for the telephone.

The researcher continued the interview by first engaging the participants by asking them to provide information on their familial situation. For example, the participants were asked if they were married, number of children and their ages, age their child was diagnosed with autism and their current age. The interview continued with questions relating to the participants' experience with having a child with autism. Questions in the section of the interview included stressors associated with having a child with autism, effects of the diagnosis on marital issues, changes in parenting after receiving diagnosis, changes in parenting skills after receiving ABA services from CARD, experience having an in home ABA program, financial issues experienced related to the ABA program, changes in relationships with family and friends, and perception of their neuro-typical child's experience with having a sibling with autism. At the end of the interview parents were thanked for their time and asked if they had any further questions for the researcher. The participants were then informed that they were going to receive the debriefing statement (Appendix C) via email which provided further information on the study, including contact information.

Data Recording

Data for this study were recorded in a notebook. No audio recording was utilized in this study because all interviews were conducted over the telephone. The answers to the questions stated above were recorded in a notebook. A second notebook was kept that contained the impressions and themes that developed during each interview.

CHAPTER FOUR

EVALUATION

Introduction

This chapter reports the findings of this study. The data were analyzed in this chapter using the post-positivist paradigm, which assesses commonalities in the participants' responses during the interviews. The study analyzed the data in order to build a theory to understand the experience of families of children with autism. Implications of the findings will also be discussed as they relate to both micro and macro social work practice.

Data Analysis

The data in this study were analyzed using post-positivist qualitative methodology. This methodology utilizes open coding, axial coding, selective coding, and the conditional matrix to discover commonalities between participant responses and build a theory based on those commonalities. Open coding is the process of extracting the data from the interview. The process of extracting the data is called micro analysis and during this process the researcher analyzed the statements in detail in order to extract the most important information and categorize that information. Next, axial coding was used to link the open codes and create a theme. The study then integrated and refined the themes to build a theory, in a process called selective coding. Finally, the implications of the theory were connected to social work practice in the conditional matrix (Morris, 2006).

Open Coding and Axial Coding

Open codes were developed after analysis of the data. The codes are explained and discussed below as they emerged from the data. From the open codes, themes developed using axial coding. These themes are identified as stress, family life, parenting, relationships, and ABA experience.

Stress

The term "stress" refers to the difficulties faced by having a child diagnosed with autism in the family. All participants stated they experienced stress related to having a child with autism. Open codes included in this theme are finances, obtaining diagnosis, and daily stressors.

Finances

"Finances" emerged as an open code during data analysis. "Finances" refers to the effect having a child with autism has on the financial state of the family. This code was chosen because many of the families in the study experienced or mentioned financial stressors due to the demands of an ABA program as well as other treatment modalities. Specifically, six of the participants expressed they experienced financial difficulties, while five participants reported no financial stress. When asked about financial stress, Interviewee #4 stated, "We have no financial issues. We are fortunate that the ABA program is fully funded." Another interviewee #5 contributed to the open code of financial stress when they stated that although their ABA program is fully paid, other factors contribute to having financial issues, including a Defeat Autism Now (DAN) doctor who charges $550 per hour, supplies for ABA program, and special dietary needs. Other data contributing to this code is from Interviewee #6 who stated "We are spending out of guilt… It is all about the money no one really cares about the kids". Data from Interviewee #10, stated "We are fighting for this program in court. We have to pay for CARD, attorney fees, school. We are broke. It is financially straining and draining".

The following figure depicts the code for finances. The axial code for finances demonstrated the participants' financial stressors as they related to having a child with autism in an ABA program.

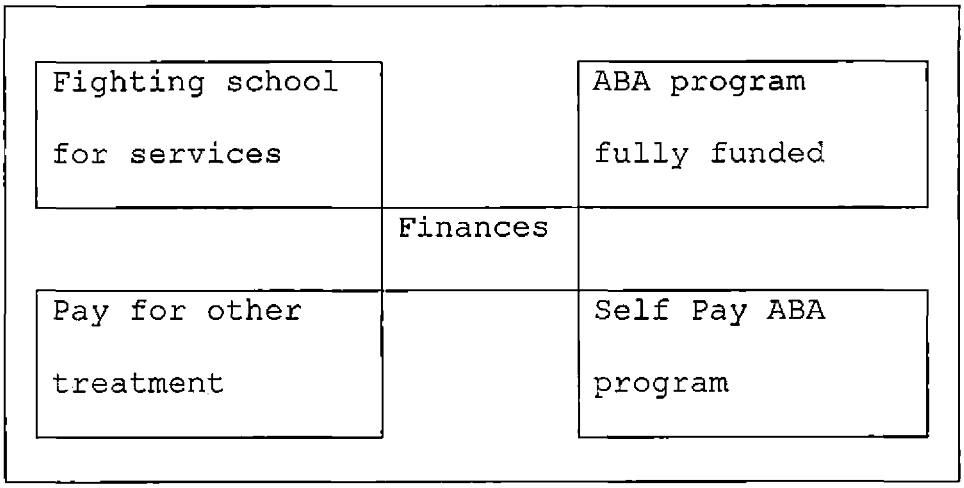

Figure 1. Finances

This chart describes the financial stressors as stated by the participants during the interview. Based on the interviews the participants shared that they either had the ABA program fully funded and therefore they did not experience financial stressors, they were funding the ABA program themselves, they were fighting the school district for ABA services, or they were experiencing financial stress due to other treatment modalities.

Obtaining Diagnosis

"Obtaining a diagnosis" is the code that refers to the process parents of children with autism go through to establish that their child has autism. This code was chosen because obtaining a diagnosis can be a stressful and emotional process. All study participants reported experiencing stress at some point during the diagnostic process. During the interview with Interviewee #5, it was noticed that there was denial of any developmental delays prior to receiving a diagnosis. Interviewee #5 stated "My wife saw the symptoms, but I was reluctant to believe it. I thought kids developed differently. Maybe I did not want to see it." Other interviews that led to this coding included Interviewee #10 who stated "I took him to two doctors to get a diagnosis. It was very stressful. When I finally got a diagnosis I was not surprised but still, completely devastated." Interviewee #1 also contributed to this code, stating she was shocked by the diagnosis and thought he might be deaf, but would have never guessed autism.

The participants either reported they knew before visiting the doctor that their child had a developmental disability or they felt their child did not have a disability. When the participants did not realize their child had a disability, they reportedly felt surprise, loss, denial, or blame. In addition, the participants also described the difficulty of receiving a diagnosis which ranged from easy, with only visiting one doctor to difficult, when the parent would consult up to four doctors to establish a diagnosis of autism for their child.

Daily Stress

The code "daily stress" was included in open coding since all participants reported increases in daily stress due to having a child with autism. Interviewee # 8 reported "It has turned our world upside down." She went on to describe that she constantly needs to plan ahead to avoid "setting him off." Interviewee #10 reports that keeping her child safe in public is a big daily stressor as he will often run off and does not understand what is dangerous. Interviewee #2 reported that it is difficult to go to public places because of embarrassment and lack of understanding from the community.

Family

The theme "family" refers to the dynamics of the interviewees' families and how having child with autism affects these dynamics. All participants reported a change in their family life after having a child with autism. The codes included in this theme are marriage, daily family life, and sibling perception.

Marriage

The code "marriage" is referred to as the impact that having a child with autism has on marriage. All participants in the study were married to the parent of their child with autism. Further, all of the study participants reported increased marital stress due to raising a child with autism, which accounted for the inclusion of this code in the analysis. For example, when asked about marriage, Interviewee #3 stated that "Marriage is tough, but we have to choose to love one another. Our own flaws are exaggerated in our child, which can be frustrating." Another example came from Interviewee #11 who stated that marriage is harder having a child with autism and that he understands why the divorce rate is so high in this population. He went on to say they are both so focused on autism and working that they have no time for each other. Interviewee #7 stated, "Before the diagnosis, my husband did not want to believe anything was wrong with our child," but since then she reports that their marriage is now stronger and they work together to do what is best for their child.

Family Life

"Family life" is the daily interactions between family members and time devoted to family life. This code was chosen because home life is a significant factor for this population since they typically are unable to socialize as normal families do. All participants reported an difficulties in maintaining a normal family life since having a child with autism. For example, when asked about the effect of having a child with autism on family life, Interviewee #8 stated "I am still mourning the loss of a normal family life" and "I am not able to see my kids' lives as I always envisioned." When asked the same question, Interviewee #11 stated "Our world is autism." He went on to describe life as he saw it for his family. He reported that the (neuro-typical) kids have lost out on experiences because the family does not do the activities they would normally do.

Sibling Perception

The code, "sibling perception" refers to the inferred experiences of the siblings living with a child with autism. Parents were asked what they felt their neuro-typical child experienced having a sibling with autism. All participants who have a neuro-typical child, reported some adjustment issues for that child related to their sibling with autism. This code was included because siblings of children with autism often have a difficult experience when dealing with the emotional issues related to having a sibling with autism. For example, when questioned about her son's perception of his brother with autism, Interviewee #1 stated "He fears his brother will embarrass him." And, "He does not tell anyone he has a twin brother." Conversely, Interviewee #5 reported that their neuro-typical child relates well with their child with autism, and has no clue anything is different about her. He also reported that they have a positive sibling relationship, as they play and fight like typical siblings. Another example is Interviewee #7 who stated that although her 10 year old daughter takes on too much responsibility for her brother with autism, her five year old son is often jealous of the attention his brother receives.

The following figure depicts the reactions siblings have to living with their sibling diagnosed with autism. The chart is divided into positive and negative reactions and emotions siblings of children with autism may experience as reported by their parents.

Reaction to Sibling with Autism

Positive	Negative
Helpful	Embarrassed
Play together	No attention
Typical relationship	Jealous
Love	Loss of experience
Thinks it's normal	Unfair

Figure 2. Reactions of Siblings

This axial coding demonstrates siblings' reactions to having a sibling with autism. Both positive and negative reactions are shown according to the interviewees' perceptions of their child's reaction to having a sibling with autism. The figure shows that although living with a sibling with autism is stressful for most siblings, they also are able to see their sibling positively.

Parenting

The theme "parenting" refers to the effects that the diagnosis of autism and ABA therapy have on the participants' parenting styles. All participants reported changes in parenting skills either after their child was diagnosed with autism or when they began receiving ABA services. The codes included in the theme "parenting" are as follows: parenting after diagnosis and parenting after ABA.

Parenting after Diagnosis

"Parenting after diagnosis," refers to the changes parents made after their child was diagnosed with autism. This code was chosen because nine parents reported a change their parenting style once they receive a diagnosis. For example, when asked about changes in parenting, Interviewee #5 stated "I try to be more patient." Further, Interviewee #5 reported a greater understanding of the behaviors that are associated with autism, and tries to understand the reasons for the behaviors. Another example is the response from Interviewee #1, who stated that after receiving the diagnosis she realized that her son was not being "naughty," and his negative behaviors were a result of autism. This has increased the awareness of the reasons behind certain behaviors and helped her to understand her child better. Finally, Interviewee #10 reported that she learned behavioral techniques on her own just after receiving the diagnosis.

Parenting after Applied Behavior Analysis

The code, "parenting after ABA," refers to changes in parenting style after receiving ABA services. All participants reported they learned skills after their child began ABA services. This code was chosen because ABA teaches parents techniques to appropriately modify behaviors. Therefore this code was an important aspect of the experience of these families. For example, when asked how parenting style changed after receiving ABA services, Interviewee #4 stated that ABA has taught her appropriate interventions that she can use with her other child. She also reported that it seems like common sense. In addition, Interviewee #6 stated that he is more aware of what he is supposed to do and it has helped him to be able to help teach his son. On the other hand, Interviewee #9 who stated "I was given tools to use but it was not too drastically helpful".

Almost all participants reported changes in parenting style after their child was diagnosed with autism. Participants reported that since beginning ABA therapy for their child, they have a greater understanding of their behaviors and were given tools that have helped them to be more effective in managing these behaviors. Further, the participants ranged from describing the techniques they learned in ABA as very helpful to mildly helpful.

Relationships

The theme "relationships" refers to the effect having a child with autism has on relationships with friends and family members, including the grandparents and siblings, as well as extended family members living outside the home. Eight participants indicated they experienced changes in relationships with friends, family, or both after their child was diagnosed with autism. The codes included in this theme are family relationships and friend relationships.

Family Relationships

The code "family relationships" refers to the family members as stated above. Seven participants reported they have experienced changes in their relationships with their family members. This code was chosen because family relationships can be very beneficial to families of children with autism since they can be a valuable resource. For example, when asked about familial relationships, Interviewee #5 stated that family is very supportive and understanding. Their parents will help out and take care of the kids when needed. Conversely, Interviewee #11 stated her family lives too far away and it is hard for them to understand because they do not spend enough time together. Another example is Interviewee #8 who stated that although her in-laws are helpful, she does not experience support from her sisters, because they do not call her or try to have a relationship with her. She added that she felt she was not up to their standards, since her children are so far behind socially and academically.

Friend Relationships

"Friend relationships" was identified as the parents' peer relationships and how having a child with autism has affected these relationships. Seven participants reported changes in their relationship with their peers after their child was diagnosed with autism. The code was chosen because it was important for the parents of children with autism to maintain a support system. However, due to the stressors attached to having a child with autism, this can be difficult since many people do not understand the experience of raising a child with autism. For example, Interviewee #5 reported that their friends do not understand, but stated "as long as we know they will never understand it's ok". He also added that he and his wife have made friends with parents of children with autism and stated that these relationships have been very beneficial in dealing with the stressors of having a child with autism. Another example was when Interviewee #10 stated that with all the stress she has experienced, "You lose what made you friends," since they do not relate to the difficulty she has faced raising a child with autism.

Relationships for families of children with autism can range from feeling understood and supported to lack of support and understanding with both friends and family members. This lack of understanding is an issue since almost all participants reported either friends or family members or both did not understand their experience and stressors related to having a child with autism.

Applied Behavior Analysis Experience

"ABA experience" refers to the experience of families of children with autism as it relates to their ABA program. The codes included in this theme are stress relief and increased stress. All participants mentioned a decrease in stress related to having an ABA program. Additionally, nine participants mentioned an increase in stress related to maintaining an ABA program. This theme and codes are not included in the theme named "stress" because the responses from the participants suggested specifically that an ABA program can both increase and decrease stress.

Stress Relief

"Stress relief" refers to how the ABA program has promoted stress relief and has benefited the family. All participants reported decreased stress since beginning their child's ABA program. This was included as a code since the benefits of an ABA program should promote stress relief. For example, when asked about their experience with their ABA program, Interviewee #2 stated that overall, since beginning ABA his stress has decreased and he feels it is an empowering approach. He also added that his son likes the program In addition, he has learned that good can come from the tantrums. Further, Interviewee #8 stated that it has helped set a routine which is helpful for the family as a whole. Finally, Interviewee #5 reported that it is helpful having professionals available to assist with any issues that arise with their child diagnosed with autism.

Increased Stress

The code, "increased stress" is the increase in stress families of children with autism experience that is directly related to having an ABA program. Seven participants reported that their child's ABA program increased their daily stress levels. This was included in the coding because although the families in this study choose to utilize ABA therapy as a treatment modality and see the benefit of the ABA program, many still experience stress related to maintaining an ABA program in their home. For example, Interviewee #10 stated that maintaining an ABA program has increased her stress because she has to run the program, which is a great deal of responsibility. In addition, she is in charge of hiring new therapist to provide the hours her son needs to increase his success. However, she adds that it is worth the stress. Another example is that Interviewee #7 noted that it is difficult to have people in your house all the time. She added that she feels she has no privacy. Finally, Interviewee #6 stated that therapists are sometime unreliable and some therapists were not trained as well as others.

The following chart depicts the issues that may increase or decrease stress in an ABA program

ABA Experience

Stress Decrease	Stress Increase
Empowering	Therapists in and out of home
Provides training and skills	Running/maintaining program
Excellent program	Very expensive
Best treatment for autism	Unreliable therapists
Decrease negative behaviors	Tantrums with therapist

Figure 3. Applied Behavior Analysis Experience

This axial chart depicts the participants' experience with an ABA program. It demonstrates that although ABA is an excellent treatment for autism, it is another stress factor for families of children with autism. However, although the families participating in this study reported that they experienced stress in the program, all participants reported that the benefits outweigh the stressors associated with having an ABA program.

Selective Coding

Selective coding is the process of building a theory. During this process the researcher incorporated and refined codes to discover a theory for families of children with autism in an ABA program. The theory that emerged through this analysis is that the families of children with autism experience familial stress related to time and balancing family life. However, the participants also have hope with the ABA program.

Familial Stress

Families of children with autism experience familial stress beyond obtaining services and managing an ABA program, as it relates to time constraints and balancing family life. This is evidenced in the themes, "stress" and "family life." The specific codes that led to this theory are "daily stressors," "marriage," "daily family life," and "sibling perception". It was found that the families of children with autism identified time constraints as a major stressor. Children with special needs often require more time than a neuro-typical child. It is likely that a child receiving ABA services takes even more time, since maintaining an ABA program is very time consuming. The study found that the amount of time the participants dedicated to helping their child diagnosed with autism did not allow them to have much leisure, or quality family time. The participants are very dedicated to their children and strive to make the best choices to help their children with autism live a more normal life.

This aspiration to have their child with autism be successful may contradict their desire for a more normal family life. The study found that the parents of children with autism work to find a sense of normalcy and stability within the family even in the circumstances of having a child with autism in an ABA program and all the stress it entails. It is important for these families to work at balancing their family as the child with autism can affect the siblings, especially as they grow older and begin to feel embarrassed by the behaviors of their sibling with autism. Younger children tend not to understand the diagnosis and may feel they are leading a normal life. However, the younger children may become jealous of the time and attention their sibling with autism receives.

Hope

Although the families of children with autism face a great deal of stress, they continue having hope that their child will be successful in their ABA program. This hope is evidenced by the theme "ABA experience." All the participants noted that although they experienced stress, lack of time, and sometimes financial burden, they felt happy that their child was getting the most appropriate intervention for the treatment of autism. These families know that the evidence points to ABA as the most successful treatment modality and continue to receive ABA services despite the stress, since it is the best option for their child.

When people are able to see distinctive changes, it provides them with hope that someday their child will have skills that will allow them to maintain a job in the community. Having hope is important to these families. This hope is empowering and helps them to continue on even when their lives are in chaos. Perhaps they are able to maintain hope, because they work as part of their child's team and are able to be actively involved in the process. Being involved in the therapy is an important factor because it allows the families to maintain a sense of control and efficacy over their lives and work toward a common goal.

Implications for Social Work Practice

The results of this study suggest that families of children with autism ought to have more resources to decrease the stress associated with having a child with autism. On a micro level, agencies could offer more social supports to help these families feel less isolated. This is important because many of the families reported that either their friends or family members did not understand their hardships. If these families are introduced to other families facing some of the same stressors, they may feel their issues are understood which may help reduce stress.

On a macro level, this study suggests that ABA therapy should be more accessible to families of children with autism, since it provides these families with a sense of hope and empowerment. ABA therapy being more available would likely reduce stress for the families who have to fight for these services. In addition, ABA therapy is an empirically based treatment modality to treat children with autism.

Overall both macro and micro social work practitioners should be aware of the stressors associated with having a child with autism and remain compassionate to their circumstances. In addition, both micro and macro practice social workers should be aware of the benefits

ABA therapy, not only for the child with autism, but for the family as well.

Summary

The previous chapter discussed the analysis of the data for this study, which was a post-positivist, qualitative study. The chapter described and demonstrated open coding, axial coding, and selective coding. In addition, this chapter described the stressors faced by the families of children with autism. Finally, this chapter discussed the implications of social work practice as they relate to the study.

CHAPTER FIVE

TERMINATION AND FOLLOW UP

Introduction

This chapter discusses how the researcher communicated the findings of this study to the study site and participants. It also discusses how the study was terminated with the study participants. The ongoing relationship between the study and the participants is also discussed in this chapter.

Communicating Findings to Study Site and Participants

The findings of this study were communicated to the study site and participants at CARD in the Temecula office. All participants were invited to attend the presentation of findings. In addition, the supervisors at the CARD office in Temecula were also invited to attend, so they would be able to communicate the information to their staff and better understand the families they serve. Finally, CARD headquarters was provided with a copy of the study so they would have access to the findings of the study.

The supervisors at CARD's Temecula office were also invited to attend the School of Social Work's annual poster days at California State University, San Bernardino. They were invited to help them gain a better understanding of the population they work so closely with.

Termination of Study

When the study was complete, the researcher terminated the relationship with the participants. The relationship with CARD was also terminated when the study was completed. The researcher terminated her relationship with the study participants at the presentation of the findings at CARD's Temecula office.

Ongoing Relationship with Study Participants

The researcher did not plan to continue an ongoing relationship with the study participants. In addition, the researcher did not plan to continue and ongoing relationship with CARD or the gatekeeper of the current study. However, the researcher planned to continue her work with children with autism and their families after completion of her Master's degree in Social Work.

APPENDIX A

INFORMED CONSENT

INFORMED CONSENT

The study you are about to participate in will explore the experience of having a child diagnosed with autism and how it affects parents personally and in family relationships. Information regarding your experience will be gathered in an interview style format. The information gathered in this study will address the issues faced by families of children with autism and may lead to better services for families of children with autism. All information attained will be solely for research purposes only and confidentiality of your answers will be maintained at all times, only the researcher and a member of CSUSB faculty will have access to the information attained during the interview. No employees at CARD will have access to any statements you make today in the interview nor will they have any knowledge of your participation in this study.

During the course of the interview you will be asked questions regarding your experience of having a child with autism. With your permission the statements you make will be audio recorded and I will take notes throughout the interview. If at any time you feel uncomfortable with any questions asked during the interview you can decline to answer that question. Participation in this study is completely voluntary and you may discontinue the participation in the study at any time without any penalty. There are no foreseeable risks associated with being a participant in the study. If you have any questions regarding this study please call Rachel Lakin 909-798-1884 or Rosemary McCaslin at 909-537-5507. This study has been approved by the Department of Social Work subcommittee of the Institutional Review Board.

An X below means that I am fully aware that this study is voluntary and that I am over 18 years old.

X ____________

I agree to audio recording of my statements during the study's interview.

X ____________

APPENDIX B

INTERVIEW QUESTIONS

INTERVIEW QUESTIONS

Topics to engage participant

Age you child was diagnosed with autism and current age.
Number of children ages of children.
Marital status.
Socio-economic status

Exploration of Parent's experience

Describe their personal experience with having a child with autism and establishing diagnosis?
Stressors having a child with autism
The affect of the diagnosis on family life
Effect of an autism diagnosis on marital issues
Describe changes in parenting style after receiving an autism diagnosis.
Describe changes in parenting style after receiving CARD services.
Describe experience of having an in home ABA program and having an ABA therapist in your home.
Stressors and stress reduction associated with having an in home ABA program.
Financial issues experienced with having a child with autism.
Describe changes in relationships after receiving autism diagnosis with other children, family, spouse /partner, and friends.
Describe perception of other children's experience with having a sibling with autism.

Wrap up Interview

Ask any questions about researcher.
Describe experience with interview.

APPENDIX C

DEBRIEFING STATEMENT

DEBRIEFING STATEMENT

The study you just participated in was to gain knowledge about the issues faced by families of children with autism in hopes to increase awareness of the struggles faced by families of children with autism and improve services to families of children with autism. Results of the study will be available after September 2009. You may contact Rosemary McCaslin at 909-537-5507 for any information on the study's outcome. Thank you for your participation in this study on the experience of families of children with autism.

REFERENCES

American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed., text rev.). Washington, DC: Author.

Benderix, Y., & Sivberg, B. (2007). Siblings experience of having a brother or sister with autism and mental retardation: A case study of 14 siblings from five families. *Journal of Psychiatric Psychology, 22*(5), 410-418.

Bristol, M. M., Gallagher, J. J., & Holt, K. D. (1993). Maternal depressive symptoms in autism: Response to psycho educational intervention. *Rehabilitation Psychology, 38*(1), 3-10.

Center for Autism and Related Disorders, Inc. (2001). *What is autism*? Retrieved on November 15, 2007 from http://www.centerfroautism.com/whatisautism

Gray, D. E. (1997). High functioning autistic children and the construction of "normal family life". *Social Science and Medicine, 44*(8), 1097-1106.

Gray, D. E. (2003). Gender and coping: The parents of children with high functioning autism. *Social Science and Medicine, 56*(3), 631-642.

Hillman, J. (2006). Supporting and treating families with children on the autism spectrum: The unique role of the generalist psychologist. *Psychotherapy: Theory, Research, Practice, Training, 43*(3), 349-358.

Kuhn, J. C., & Carter A. S. (2006). Maternal self-efficacy and associated parenting cognitions among mothers of children with autism. *American Journal of Orthopsychology, 76*(4), 564-575

Mandell, D. S., Walrath, C. M., Manteuffel, B., Sgro, G., & Pinto-Martin, J. A. (2005). The prevalence and correlates of abuse among children with autism served in comprehensive community based mental health settings. *Child Abuse and Neglect, 29*(12), 1359-1372.

Martin, J. M., & Cole, D. A. (1993). Adaptability and cohesion of dyadic relationships in families with developmentally disabled children. *Journal of Family Psychology,* 7(2), 186-196.

McDonald, T. P., Poertner, J., & Pierpont, J. (1999). Predicting caregiver stress. *Journal of Orthopsychology, 69*(1), 100-109.

Morris, T. (2006). *Social work research methods: Four alternative paradigms.* Thousand Oaks, CA: Sage Publications, Inc.

Siklos, S., & Kerisk, A. (2007). Assessing the diagnostic experience of a small sample of parents of children with autism spectrum disorders. *Research in Developmental Disabilities, 28*(1), 9-22.

Zastrow C., & Kirst-Ashman, K. (2007). *Understanding human behavior and social environment* (7th ed.). Belmont, CA: Brooks/Cole