EXPLORATION OF PARENT PERSPECTIVES AND ADAPTATION TO SHAKEN BABY SYNDROME: AN OCCUPATIONAL THERAPY APPROACH

A DISSERTATION

SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS

FOR THE DEGREE OF DOCTOR OF PHILOSOPHY

IN THE GRADUATE SCHOOL OF THE

TEXAS WOMAN'S UNIVERSITY

COLLEGE OF HEALTH SCIENCES

GAIL A. POSKEY, B.S., M.O.T.

DENTON, TEXAS

DECEMBER 2007

TEXAS WOMAN'S UNIVERSITY
DENTON, TEXAS

September 27, 2007

To the Dean of the Graduate School:

I am submitting herewith a dissertation written by Gail A. Poskey entitled "Exploration of Parent Perspectives and Adaptation to Shaken Baby Syndrome: An Occupational Therapy Approach." I have examined this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy with a major in Occupational Therapy.

Gayle Hersch, Ph.D., Major Professor

We have read this dissertation and recommend its acceptance:

Director, School of Occupational Therapy

Accepted:

Dean of the Graduate School

ACKNOWLEDGEMENTS

I would like to acknowledge many individuals who have contributed to this dissertation process. I would like to thank my entire dissertation committee for their guidance and support. Specifically, Dr. Ron Fannin for his contributions and for serving as my outside committee member, Dr. Cathy Candler for her support, consistency and guidance, and the late Dr. Jean Spencer for her encouragement and guidance to pursue this topic. I would especially like to thank the chair of my committee, Dr. Gayle Hersch, for her unwavering support and consistent encouragement. Her guidance, dedication, mentorship and friendship helped keep me focused and determined to complete my dissertation.

I would like to thank my dear family, who listened, offered their patience and encouragement during this process but mostly, believed in me. I am also grateful to my colleagues at Baylor University Medical Center, who provided encouragement, always a listening ear and flexibility with my work schedule.

Lastly, I would like to extend my gratitude to all of the participants who so willingly gave of their time, support and commitment to this research process. I am indeed grateful for their involvement.

ABSTRACT

GAIL A. POSKEY

EXPLORATION OF PARENT PERSPECTIVES AND ADAPTATION TO SHAKEN BABY SYNDROME: AN OCCUPATIONAL THERAPY APPROACH

DECEMBER 2007

Shaken Baby Syndrome is a violent and deadly form of child abuse. However, it is a preventable tragedy. Infant crying is the major precipitating factor that causes an adult to shake an infant or small child. The purpose of this research was to examine from an occupational therapy perspective current prevention strategies of Shaken Baby Syndrome (SBS) and to explore adaptive strategies used by parents in response to inconsolable infant crying.

The first study provided a program evaluation of a parent education class. The parent education class was developed to address infant crying and the dangers of SBS and provided primary prevention for parents and caregivers with infants in a neonatal intensive care unit. The study established that the participants did perceive the class to be an effective method of addressing infant crying and conveying the dangers of SBS.

The second study included a qualitative inquiry utilizing a phenomenological tradition to explore the parent's perspective on the lived experience of infant crying. In-depth interviews with six parents who had directly experienced the phenomenon of infant crying were conducted. The themes of: longing for answers, heightened emotions and

coping strategies emerged from the data. A discussion of these themes along with clinical implications for practice and future research are presented.

Caregiving with an infant is considered a co-occupation, thus the infant and parent's response to infant crying is viewed as a co-occupation. The parent's thoughts, feelings, behaviors and actions in response to infant crying were explored in the third study by using a qualitative research approach of participant observations, a questionnaire and field notes. The results of the analysis identified three major themes: the immediate response to crying, routines, and utilizing movement as a coping strategy.

Lastly, Chapter 6 offers a summary of the key findings from the three research studies. This section of the dissertation provides a synthesis of the studies, suggestions for future research, and implications for occupational therapy practice in SBS prevention programs.

TABLE OF CONTENTS

LIST OF TABLES

CHAPTER I

INTRODUCTION

Child abuse is a disturbing reality within the United States and unfortunately violence involving children is an everyday occurrence (Gutierrez, Clements & Averill, 2004). Within the field of occupational therapy, it is highly probable a therapist will provide intervention to a client who is a victim of violence (MacDonald & Helfrich, 2001), and often times this violence happens to children. Even more disturbing is when intentional violence causes serious injury or death to a helpless infant or young child.

Statement of the Problem

Shaken Baby Syndrome (SBS) is a violent and one of the most deadly forms of child abuse. It is, however, a preventable tragedy. Inconsolable infant crying is the main factor that leads to SBS. A limited number of research studies exist within the field of occupational therapy examining factors related to SBS. Occupational therapists have a unique opportunity to contribute to the primary prevention of Shaken Baby Syndrome. Occupational therapy can take an active role in establishing primary prevention programs and document and disseminate these prevention programs with other clinicians and professionals in the fight against SBS.

Statement of the Purpose

The dual purpose of this research was to examine from an occupational therapy perspective current prevention strategies of Shaken Baby Syndrome and to explore

adaptive strategies used by parents in response to inconsolable infant crying. Infant crying is the major precipitating factor that causes an adult to violently shake an infant or small child. There are recommended strategies and methods for parents to handle their stress and frustration in dealing with infant crying; however, each parent or caregiver may handle crying differently. What typifies SBS is that the parent or caregiver demonstrates difficulty in dealing with stress and poor impulse control during their occupational role of responding to infant crying. This dissertation consisted of 3 studies focusing on parent education of infant crying and exploring how parents adapt and handle inconsolable infant crying.

Specific Aims

This line of research consisted of three studies; the title and purpose of each study is outlined below:

Study I: Shaken Baby Syndrome: A Program Evaluation of a Parent Education Class

The study consisted of a program evaluation of a parent education class. The purpose of the study was to determine the parent's perceived effectiveness of the educational class and to identify additional strategies the parents found helpful in responding to a crying infant.

The research questions were:

1) How does the content of the education class address the topic of parents/caregivers dealing with infant crying and to what extent do the participants find the class informative of the dangers of SBS?

2) How likely will the participants share this information with others who care for their child?

3) How have the participants enlisted any strategies and/or information they acquired in the class in responding to their crying infant and what additional strategies if any have the participant's developed in responding to their crying infant?

4) What percentage of the participants completed the Statement of Commitment?

See Appendix B for data collection forms for Study I.

Study II: Listening to their Voices: Parents' Perspectives on Infant Crying

This study consisted of a qualitative research study. A phenomenological tradition was utilized for this study. The purpose was to explore the parents' perspectives on the lived experience of infant crying. The research questions were:

1) How do the parents react to infant crying?

2) How does the parent cope with infant crying and what type of techniques or interventions do they use to help with infant crying?

3) How is excessive crying or inconsolable crying described by the parent?

4) What time of the day does the infant cry?

See Appendix C for data collection forms for Study II.

Study III: Exploring Co-Occupations: Parents' Responses to Infant Crying

The third study, a qualitative inquiry, involved participant observations with parents involved from Study II. The purpose of the study was to glean specific behaviors, actions, and emotions in which the parents engage when responding to infant crying. The research questions were:

1) What is the parent's behavior when their infant is crying?

2) What are the types of activities in which the parent engages when responding to their crying infant?

3) How does the parent describe their feelings when responding to infant crying?

See Appendix C for data collection forms for Study III.

Researcher's Perspective

I have worked with several infants and children who have been victims of SBS and have seen firsthand the devastation caused by this form of child abuse. Although the results of SBS are irreversible, the opportunities for prevention and education of parents and caregivers are plentiful. I currently work with preterm infants and their parents and often have the opportunity to discuss strategies to cope with infant crying, to promote understanding why an infant cries and to provide education on the prevention of SBS. Also, I have an interest in exploring how parents respond, behave and cope with crying in regard to their infant, I hope to provide further insight into this area of study and perhaps offer additional intervention practices for occupational therapy to be involved in the prevention of SBS.

CHAPTER II

BACKGROUND AND SIGNIFICANCE

Introduction

Childhood is typically a time of growth, fun and innocence. However, child abuse is a disturbing reality within the United States, and unfortunately violence involving children is an everyday occurrence (Gutierrez, Clements & Averill, 2004). Every day four children in America die as a result of child abuse or neglect, and almost half of the deaths are children who are younger than 1 year of age (Prevent Child Abuse America, 2006). This violence occurs as a part of everyday life for thousands of children (Hornor, 2005). It occurs all too often in an environment that is supposedly safe, warm and accepting; that environment is quite frequently the infant's home. Child abuse and neglect are devastating and can be deadly.

Shaken Baby Syndrome (SBS) is a form of child abuse. According to the National Center for Shaken Baby Syndrome, approximately 1,400 cases are reported each year and 25% to 30% of these victims die as a result of shaking (National Center for Shaken Baby Syndrome, 2005). The remaining victims may have complications that will last a lifetime. It is estimated that 50,000 cases of SBS occur each year in the United States (American Association of Neurological Surgeons, 2000).

SBS is a preventable form of child abuse. Infant crying is the major precipitating factor of shaking an infant (Nakagawa & Conway, 2004); however, crying is a normal and healthy part of development.

Shaken Baby Syndrome is a violent and one of the most deadly forms of child abuse. It is, however, a preventable tragedy. Occupational therapists have a unique opportunity to contribute to the primary prevention of Shaken Baby Syndrome. As MacDonald and Helfrich (2001) noted, it is highly probable an occupational therapy practitioner will provide assessment and intervention to someone who is a victim of violence. Even more disturbing is when this intentional violence causes death or serious injury to a helpless infant or young child.

This chapter will provide the background and significance of examining the topic of: Shaken Baby Syndrome, infant crying, education and prevention of SBS and the relevance and importance of prevention of SBS to occupational therapy.

Shaken Baby Syndrome

In 1946, John Caffey, an American pediatric radiologist, published an article describing long bone fractures and intracranial bleeding in children who had no signs of external trauma (Caffey, 1946). However, it was not until 1971 when a British pediatric neurosurgeon, Norman Guthkelch, (Guthkelch, 1971) linked subdural hematomas and whiplash shaking injuries in infants and addressed the biomechanics of these types of injuries. Then in 1972, Caffey (1972) reported a collection of clinical findings of brain swelling, subdural or subarachnoid hemorrhages, and retinal hemorrhages in infants who

had no external head trauma. Caffey (1974) identified these findings as whiplash shaken infant syndrome (WSIS) which today we now call Shaken Baby Syndrome (SBS).

Mechanisms of Injury

SBS occurs when the perpetrator grabs the infant under the arms in a face to face position and forcefully shakes the infant by moving the child from full extension of the arms to a position close to the chest, which causes the infant's head to move back and forth very rapidly (Alexander & Smith, 1998; Nakagawa & Conway, 2004). The American Academy of Pediatrics describes "the act of shaking leading to shaken baby syndrome is so violent that individuals observing it would recognize it as dangerous and likely to kill the child" (2001, p. 206). To replicate the difference in size between an infant and a average man, Alexander and Smith (1998) state, "the man would have to be violently shaken by a 2,000 lb gorilla. Clearly, the neck muscles would be overwhelmed, and small differences in brain density would be insignificant when considering the violence of the action" (p. 20).

The acceleration-deceleration and rotational forces caused from the shaking has a significant effect on the immature nervous system of the infant. It is important to note infants are more vulnerable to whiplash shaking injuries than adults due to the infant's relatively large head to body ratio, which is supported by weak neck muscles, the incomplete myelination of the white matter and larger subarachnoid spaces of the infant's brain (Castiglia, 2001). Conway (1998) addresses how the infant's brain is located in a poorly supported and under-developed skull and is extremely vulnerable to the shearing forces which occur with acceleration-deceleration injuries. Furthermore, the central

nervous system is not fully developed at birth and is susceptible to injuries which may have long-term and significantly debilitating consequences (Castiglia).

The damage to the victims of SBS is devastating and widespread. Death results in 25 to 30% of reported cases. The survivors of severe injury may face significant neurological impairment of cortical blindness, seizure disorders, profound mental retardation, spastic diplegia or quadriplegia, while other victims of SBS may live in a persistent vegetative state (Alexander, Levitt, and Smith, 2001). Those victims who suffer from less severe injuries may demonstrate milder mental retardation, developmental delays, learning disabilities, behavior problems, personality changes and possible seizure disorders. It is also estimated that approximately one third of the victims who are shaken may escape without significant handicapping conditions (Alexander et al.). Hundreds of the survivors receive rehabilitation services and occupational therapy is often times a vital part of the rehabilitation team.

Victim and Perpetrator Characteristics

The victims of SBS, as previously mentioned, are usually young children under one year of age. Male infants have a slightly higher risk of being shaken than female infants. Those infants who may be at a high risk include: children born prematurely, an infant with a disability or chronic illness, infants born to mothers who did not receive prenatal care, children of parents who are poorly educated, and parents younger than 18 years of age and lower socioeconomic backgrounds (Duhaime, Christian, Rorke, and Zummerman, 1998; Simons, Downs, Hurster, and Archer, 1996;).

The perpetrators of SBS can be any individual, including a mother, a father, baby sitters, child care workers, mother's boyfriend, siblings or grandparents; anyone with adult strength is capable of shaking an infant or small child. The notion that anyone could be a perpetrator of SBS should be reinforced with caregivers and parents (Peinkofer, 2002). The majority of individuals who shake infants do not fall into any specific category; however research notes that certain characteristics actually make a person more at risk of being a perpetrator of SBS. Studies indicate males are responsible for approximately 60% to 70% of all reported SBS cases (Lazoritz, Baldwin and Kini, 1997; Butler, 1995). Those being at particularly higher risk are the father of the child and the mother's boyfriend or stepfather, while baby sitters and mothers make up another percentage of the perpetrators.

What causes someone to perform this violent form of child abuse of shaking a baby? The number one trigger for shaking infants is inconsolable crying (National Center on Shaken Baby Syndrome, 2005). Those who have shaken babies are unable to control their frustration and anger. Usually the caregiver did not shake the child with the intent of hurting them, they shook the child in a moment of frustration, thinking the shaking would help calm the child and stop the crying (Castiglia, 2001). Visualize this scenario: an infant is crying and crying, and a caregiver or parent, unable to cope with the crying, in a split second of frustration and exhaustion grabs the infant and violently shakes them, perhaps in an attempt to control the infant's behavior. However, the damage and end results are irreversible, this being a tragedy which was preventable. Physicians Alexander and Smith (1998) describe a case in which they encountered a deaf

father. The father confessed to violently shaking his child. Even though he could not hear the child crying, he could see his child crying and felt he had to control and stop the crying.

Other events may trigger shaking; those include feeding difficulties, infant irritability, and toilet training. Additional factors that may contribute to the caregiver's stress level include: unrealistic expectations of the child, inexperience in caring for a child, social stressors, a careless disregard for the child's safety, or little understanding of early infant crying (National Center on Shaken Baby Syndrome, 2003; Nakagawa & Conway, 2004). Therefore, it is paramount to show the relationship/link of crying to SBS and educate others on the dynamics of infant crying.

Crying

Infant crying has long been a topic of study for physicians, parents, professionals and scientists (Murry & Murry, 1980). Crying is considered a behavior, an acoustic, social but yet a communicative event which conveys information regarding the infant's basic needs and their nervous system (Lester, 1985). Crying is a normal part of infant behavior and development; it is the infant's way of communication. Crying is a behavior and the primary mode for the neonate and young infant to express and communicate their basic needs (Lester, 1985). As Barr and colleagues note, crying is now understood to be a sign, as well as a symptom of a problematic function; crying is viewed as a signal in interactive contexts (Barr, Hopkins, & Green, 2000).

Crying in infancy is the earliest and one of the most compelling infant signals. (Barr, Konner, Bakeman & Adamson, 1991). Research over the last 50 years has revealed

normal crying behavior does have a pattern. This predictable pattern is seen during the first year of life. Wessel and colleagues (Wessel, Cobb, Jackson, Harris & Detwiler, 1954) made reference to certain times of the day when infants would cry more; Brazelton (1962) also noted an infant crying curve from a study of 80 infants. Since then other studies have confirmed the earlier research and shown that the crying pattern of infants is characterized by an increase in crying at 2 weeks of age with the peak of crying seen at 6 to 8 weeks of age, then a gradual decrease in crying until 4 months (Hunziker & Barr, 1986; Barr, 1990). Other studies have shown preterm infants follow this same crying curve based on their corrected age (Barr, Chen, Hopkins, & Westra, 1996). In addition infant crying has a diurnal rhythm showing clustering in the late afternoon and early evening (Brazelton, 1962; Hunziker & Barr, 1986; Barr 1990).

Crying is the highest state of infant arousal. The rhythmical pattern of this robust crying is quite common to caregivers and parents. The cry of an infant may serve many purposes. The cry may be a result of pain and a way to communicate hunger, fatigue, discomfort or displeasure in being separated from their caregiver (Ludington-Hoe, Cong, & Hashemi, 2002). Researchers believe in the first few months of life, crying is a signal for attention (Barr, 2004). The purpose of the cry then develops into a feedback system between the infant and adult. The cry is a potent signal for the infant. The cry is designed to elicit a maternal response, with the response changing the infant's physiologic condition or to provide caregiving (Ludington-Hoe, et al.). When an infant cries, the crying gets the attention of the parent, who in turn interacts with the infant to calm and soothe them, often times with the parent holding the infant (Barr, 2004). As

stated by Barr (2004), "crying thus creates a process in which parents become attuned to and learn about their new infant" (p. 1).

However, in spite of its role in communication, excessive infant crying can be one of the most difficult aspects of parenthood (Long & Johnson, 2001). This same crying can often times cause the parent frustration and stress, provoke feelings of anger, guilt, despair, and significantly increase the risk of nonaccidental injury to the infant (Frodi, 1985; Crowe & Zeskind, 1992). Inconsolable crying is the major precipitating factor in Shaken Baby Syndrome (Nakagawa & Conway, 2004). The shaking typically results from tension and frustration generated by a baby's crying or irritability (American Academy of Pediatrics, 2001).

Education and Prevention of SBS

Education on the dangers of shaking an infant and strategies to cope with infant crying are highly noted in the literature of SBS as recommended prevention measures. Showers (1992) notes that prevention of SBS begins with education of parents and other caregivers. Nakagawa & Conway (2004) advocate that education is the key in the prevention of SBS by educating young parents and caretakers. They conclude aggressive education may hopefully reduce injuries and improve outcomes.

A important area in addressing coping with crying is to reassure parents that crying is a normal and healthy process for infants and that the crying will stop in time. Key points to include in education programs on SBS are: information on the infant crying, ideas to help calm a baby, the dangers of SBS and how to handle their potential feelings of frustration and anger in dealing with infant crying. Although there are many

recommended strategies and techniques to help calm a crying infant, what works best for one parent may not work for another. The initial coping strategies suggest parents check to see if the infant's basic needs are met. That includes: are they hungry, cold, in need of burping, in pain or require a diaper change. If the crying persists, the parents are encouraged to enlist soothing or calming techniques. Barr (2004) recommends six different techniques: swaddling, movement, touch, sounds, warmth and something different – a distraction. However, when all strategies or attempts to soothe the crying fail, and the parent feels frustration and loss of control, they are encouraged to put the baby down in a safe place and take a break and time to care for themselves.

Several hospital based prevention programs have been documented in the literature. A recent successful program was in an eight county region of western New York. Dr. Mark Dias and colleagues (2005) implemented a hospital based, parent education program that targeted all parents of newborns at the time of the infant's birth. The results of this program showed the incidence of abusive head trauma decreased by 47% over a six year period. The program involved viewing an 11 minute video discussing the dangers of shaking an infant with suggestions to handle inconsolable infant crying. The parents were also given a one page leaflet on preventing SBS and were asked to sign a voluntary commitment statement. The parents viewed the video and received the leaflet prior to discharge from the hospital (Dias, et al, 2005). This hospital based prevention program documented the ultimate goal of all prevention programs, a decrease in the incidence of reports of SBS.

Showers (2001), who has developed various successful prevention programs, advocates that the responsibility of SBS prevention does indeed belong to every professional who works with children and families and to each person who cares for a baby or young child. Therefore, occupational therapy has many opportunities to join other professionals in the campaign against SBS.

Occupational Therapy Perspective

SBS is devastating and disturbing but also a preventable tragedy. An important factor in addressing primary prevention from an occupational therapy perspective is to educate ourselves, other clinicians and students on SBS, particularly therapists who work with infants, children and caregivers. By having an understanding and good knowledge base of SBS, clinicians are better equipped to inform others on the dangers of shaking infants and strategies to prevent SBS (Poskey, 2005).

Primary prevention efforts on the dangers of shaking an infant, anger management, and adaptive coping strategies are critically important components to include in the education of SBS. What typifies SBS is the parent or caregiver demonstrates difficulty in dealing with stress and poor impulse control during their occupational role of responding to infant crying.

The occupational adaptation frame of reference (Schkade & Schultz, 1992; Schultz & Schkade, 1992) provides a framework to explore the demands of the environment upon the parent or caregiver in their occupational role and the challenges of responding to infant crying. In facilitating a healthy occupational adaptation process, it is the intent that

the parent/caregiver becomes the agent of change and develops competence in addressing infant crying.

Many occupational therapist have encountered victims of SBS in their clinical practice, another avenue to address SBS is primary prevention. Hundreds of occupational therapists interact and provide client-centered care with parents and children on a daily basis and therefore are in a good position to be advocates who can develop and establish primary prevention programs. Occupational therapy has many opportunities to explore and implement prevention programs by providing education and training to parents and caregivers on topics such as: understanding infant crying, strategies to cope with a crying infant, and how to manage anger and frustration when an infant is crying. Examples of settings appropriate for prevention programs include: early childhood intervention programs, home health, school systems, hospitals, obstetric or pediatrician's offices, and inpatient and outpatient pediatric settings (Poskey, 2005). Scaffa and colleagues (2001) note occupational therapy has a rich potential to have an impact in the area of injury prevention especially because of our unique contribution on the perspectives of occupation.

Because of this unique understanding of occupations, we are in a position to further explore and understand one aspect of the occupational role of parenting, in this case, the parent's response to infant crying. Llewellyn (1994) notes occupational therapy is well placed to further explore parenting from a participant perspective. In describing the occupational role of responding to infant crying, it is important to acknowledge the co-occupations of caregiving. Activities that are considered co-occupations require more

than one person's involvement; for instance, in the caregiving of an infant, you have both the parent and the child (Zemke & Clark, 1996). Olson (2004) states there are actually two actors for every occupation of caregiving. An example of a co-occupation of caregiving would be feeding; the parent prepares the infant's bottle and feeds the infant, the infant in turn performs the task of eating and also has their need of hunger satisfied (Olson). Researchers believe in the first months of life, infant crying is a signal for attention (Barr, 2004). The purpose of the cry then develops into a feedback system between the infant and adult. As the parent attempts to comfort and respond to infant crying, the response of comforting the infant is considered a co-occupation. The crying requires some type of a response from the parent and the infant, in turn, is expressing a sign, signal or even a symptom of a problem (Barr, Hopkins, & Green, 2000) to elicit a response from the parent. The interaction of a co-occupation, then, occurs between them.

Historically, prevention programs within the profession of occupational therapy have addressed tertiary prevention at mainly individual levels. The role of occupational therapy in primary prevention is supported in several professional documents. Those include: the *Guide to Occupational Therapy Practice* (Moyers, 1999) and *Occupational Therapy in the Promotion of Health and Prevention* (Brownson & Scaffa, 2001). In addition, the *Occupational Therapy Practice Framework: Domain and Process supports health promotion and prevention* (AOTA, 2002).

The national document, *Healthy People 2010,* provides a comprehensive national health promotion and disease prevention plan and identifies 28 focus areas. Injury and violence prevention is listed as a focus area and *Healthy People 2010* encourages and

promotes interdisciplinary efforts. Previous examples were discussed for establishing prevention programs in more traditional work settings, however, community based intervention is another avenue to establish occupational therapy prevention programs. Those may include baby-sitting classes, in-services for child care facilities, community agency staff training, and presentations at various community and civic organizations. In providing community based intervention and networking with community agencies, governmental agencies, and federal, state and local prevention agencies, therapists can expand their role beyond traditional approaches to encompass primary prevention strategies.

As occupational therapists, we bring valuable knowledge, insight and experience on participation and occupation to support our efforts of collaborating, consulting and contributing to the prevention of SBS. It is hoped and encouraged that occupational therapy practitioners will join forces with other professionals in helping to prevent SBS. The results of SBS are irreversible; however, the opportunities for prevention and education of parents and caregivers are plentiful. Perhaps these prevention programs, simply stated, will make a difference in saving the life of an innocent child.

CHAPTER III

SHAKEN BABY SYNDROME: A PROGRAM EVALUATION OF A PARENT EDUCATION CLASS

Submitted for publication to Occupational Therapy in Health Care Journal

Introduction

Childhood is typically a time of growth, fun and innocence. However child abuse is a disturbing reality within the United States, and unfortunately violence involving children is an everyday occurrence (Gutierrez, Clements & Averill, 2004). Every day four children in America die as a result of child abuse or neglect, and almost half of the deaths are children who are younger than 1 year of age (Prevent Child Abuse America, 2006). This violence occurs as a part of everyday life for thousands of children (Hornor, 2005). It occurs all too often in an environment that is to be supposedly safe, warm and accepting; that environment is quite frequently the infant's home. Child abuse and neglect are devastating and can be deadly.

Shaken Baby Syndrome (SBS) is a form of child abuse. According to the National Center for Shaken Baby Syndrome, approximately 1,400 cases are reported each year and 25% to 30% of these victims die as a result of shaking (National Center for Shaken Baby Syndrome, 2005). It is estimated that 50,000 cases of SBS occur each year in the United States (American Association of Neurological Surgeons, 2000).

SBS is a preventable form of child abuse. Infant crying is the major precipitating factor of shaking an infant (Nakagawa & Conway, 2004); however, crying is a normal and healthy part of development. It is the infant's way of communicating.

Shaken Baby Syndrome is a violent and one of the most deadly forms of child abuse. It is, however, a preventable tragedy. Occupational therapists have a unique opportunity to contribute to the primary prevention of Shaken Baby Syndrome. As MacDonald and Helfrich (2001) noted, it is highly probable an occnpational therapy practitioner will provide assessment and intervention to someone who is a victim of violence. Even more disturbing is when this intentional violence causes death or serious injury to a helpless infant or young child. While many occupational therapists have encountered victims of SBS in their clinical practice, another avenue to address SBS is through primary prevention programs. Hundreds of occupational therapists interact and provide client-centered care with parents and children on a daily basis and therefore are in a good position to be advocates who can develop and establish primary prevention programs. Occupational therapy has a rich potential to have an impact within the area of injury and violence prevention especially because of our unique understanding of occupations (Scaffa, Desmond & Brownson, 2001).

Purpose

Based on this unique understanding of occupations, a parent education class was developed by an occupational therapist. This parent education class on infant crying and the dangers of SBS was established to provide primary prevention for parents and caregivers who had infants in the neonatal intensive care unit (NICU). This study used a

program evaluation design to determine the parent and/or caregiver's perceived effectiveness of the educational class and to identify additional strategies the parent and caregiver's found helpful in responding to a crying infant. The research questions were: 1) How did the content of the education class address the topic of parents/caregivers dealing with infant crying and to what extent did the participants find the class informative of the dangers of SBS? 2) How likely would the participants share this information with others who care for their child? 3) How have the participants enlisted any strategies and/or information they acquired in the class in responding to their crying infant and what additional strategies if any have the participant's developed in responding to their crying infant? 4) What percentage of the participants completed the Statement of Commitment (SOC)?

Literature Review

Shaken Baby Syndrome

SBS occurs when an adult caregiver violently shakes an infant or small child. In reports of shaken baby cases, adults were unable to control their frustration and anger and shook the infant in an attempt to stop the crying (Castigila, 2001). The physical characteristics of SBS include intracranial bleeding, cerebral edema and retinal hemorrhages which result from repetitive acceleration, deceleration, and rotational forces (Nakagawa & Conway, 2004). The results of these injuries may contribute to a lifetime of problems such as severe neurological impairment or even death to these tiny victims.

The victims of SBS are typically less than 1 year old, with the peak incidence occurring between 6 weeks and 6 months of age, and boys are affected slightly more than

girls (Nakagawa & Conway, 2004). The perpetrators can be any individual, including mothers, fathers, baby-sitters, day-care workers, siblings; any individual with adult strength is capable of shaking an infant. The notion that anyone could be a perpetrator of SBS should be reinforced with parents and caregivers (Peinkofer, 2002). Research notes males are responsible for 60% to 70% of all reported SBS cases (Butler, 1995; Lazoritz, Baldwin & Kini 1997).

Infant Crying

An infant's cry is the earliest and one of the most compelling of infant signals (Barr, Konner, Bakeman, Adamson, &, 1991). Crying is the infant's basic form of communication. All children cry while some cry more than others. However, crying is a normal part of infant behavior and development. Infant crying begins to increase at 2 weeks and peaks at 6 to 8 weeks with a decline in the third and fourth month while the crying may last 2 to 3 hours a day with crying bouts seen more in the late afternoon and the evening (Brazelton, 1962; Hunziker & Barr, 1986, Barr, 1990). Other studies have shown preterm infants follow this same crying curve based on their corrected age (Barr, Chen, Hopkins, & Westra, 1996).

Crying is able to elicit strong emotional responses in parents which, in turn, may affect parent-infant interactions (Lester, 1985). Crying is a signal which communicates to the parent or caregiver to investigate the cause of the infant's distress. However, inconsolable crying is the precipitating factor in shaken baby syndrome, often times the tension and frustration generated by the baby's crying or irritability leads to shaking.

(American Academy of Pediatrics, 2001). Therefore, it is paramount to show the relationship/link of crying to SBS and educate others on the dynamics of crying.

Methodology

Participants

The 33 participants in this study consisted of parents and caregivers of hospitalized infants from a Level III NICU of a large not-for-profit hospital in a large southwest city who attended the "Why Babies Cry: How to cope with a crying and fussy baby" parent education class. The parents and caregivers elected to participate in the existing education class which was offered three times a month. Participants were recruited by flyers posted in the NICU and by referral and word of mouth from the occupational therapists, registered nurses, and family care coordinators of the NICU. Inclusion criteria for the study consisted of participants who were able to understand, read, write, and follow instructions in English. Other inclusion criteria were participants would be between ages 18 and 75 years. Participants younger than 18 or older than 75 years were allowed to attend and participate in the education class.

At the end of each class the participants were invited to participate in the study. Those who volunteered were asked to complete a questionnaire, sign the Statement of Commitment (SOC), and participate in a telephone follow-up. A consent to participate in the questionnaire and telephone follow-up were contained in the introductory paragraph of the questionnaire. The study was approved by the Institutional Review Boards of the hospital and by the university.

Description of the Parent Education Class

The parent education class consisted of a single session lasting 30 to 45 minutes held in the family conference room of the NICU. This is an ongoing education class that was implemented in April 2005 by the primary researcher under the umbrella of her role as an occupational therapist practicing in the NICU. The function of the class (Poskey, 2005) is to provide information for NICU parents and caregivers on infant crying, ideas to help calm a baby (Barr, 2004) and the dangers of SBS. The participants in this study were all given written information and also participated in open discussion/dialogue on: resources for infant crying, how to calculate adjusted age for prematurity, suggestions on coping strategies to help calm a crying baby, the dangers of SBS, and handling of their potential feelings of frustration and anger when dealing with a crying infant. A 10 minute DVD entitled, *When Babies Cry*...(Shaken Baby Alliance, 2004) was also shown during the education class. The DVD, produced in the same geographical area as the hospital, provided additional information on infant crying, suggestions for strategies to cope with infant crying, SBS, and documentaries from families whose child was a victim of shaken baby syndrome. The class provided interaction and dialogue with other parents and caregivers and brochures on SBS and infant crying were distributed.

Tools

The questionnaire, a modified version used in similar hospital based prevention programs (Dias, Smith, deGuehery, Mazur, Li & Shaffer, 2005; Showers, 2001), was used to assess the parent's perceived effectiveness of the education class. The twelve item questionnaire contained 1) basic demographics 2) the participant's evaluation of the

education class and 3) consent to be contacted for a telephone follow-up. The responses from the questionnaire and telephone follow-up were utilized to answer the research questions. The questionnaire was designed as a simple self-administered format for the participants. The majority of the questions were forced choice responses and dichotomous questions. The telephone follow-up consisted of five questions referring to did the participants find the strategies/interventions discussed in class helpful, what particular strategies/interventions had they utilized, had they shared the information from the class with others, and other additional strategies/interventions they had utilized in responding to infant crying.

The voluntary SOC, a version adapted by the researcher from successful and similar hospital based prevention programs (Dias et al. 2005; Showers, 2001) was utilized to demonstrate active parent participation. The function of the SOC was to affirm the parent and caregivers' receipt and understanding of the materials provided in the education class and their acknowledgement and understanding that shaking an infant is dangerous.

Data Analysis

Data analysis occurred through descriptive statistics and description of the questionnaire, telephone follow-up and the SOC. Each response on the questionnaire was analyzed for the frequency/percentage. The data were analyzed to see if there was any correlation between age, gender or education.

The open-ended questions on the questionnaire and telephone follow-up were analyzed through thematic analysis with direct quotes illustrating the themes. Field notes were kept by the researcher to allow for description and reflection.

Results

Participants

The demographics of the participants are shown in Table 1. The sample was predominantly women (73% and 27% men) with the average age of 31 years for all participants. The average age for women was 31 years and the average age of the men in the study was 29 years. Thirty-six percent of the participants had attended some college as their highest level of education. All participants were either a parent or a caregiver of an infant in the NICU. Relationships included 61% of the participants were mothers, 24% were fathers, 12% grandmothers and one uncle. Further demographic information is contained in Table I.

Questionnaire Results

All of the thirty-three participants (100%) participated in the study and completed the questionnaire. The participants in this study were all given written information and also participated in open discussion/dialogue. Based on the responses from the questionnaire, 67% of the participants had previously heard of ways to cope with a crying infant while 33% of the participants said this was the first time they had heard of ways to cope with a crying infant. Every participant found the DVD helpful according to their responses noted on the questionnaire.

Approximately 97% of the participants had previously heard that shaking an infant was dangerous. One hundred percent of the participants listed that the information discussed in the class was helpful. All of the participants responded they thought the education class would be helpful for other parents or caregivers to attend, and all participants answered they would share the information received in the education class with others who cared for their infant.

Questionnaire Comments

The comments from the open-ended questions on the questionnaire were analyzed and coded for prominent themes. The two themes emerged from the comments in response to the education class: Helpful and informative class and the importance of sharing with others.

Theme: Helpful and Informative Class. This theme emerged as participants commented on the helpfulness of the content of the education class. The participants were particularly expressive of how they viewed the class as informative. A new father expressed, "It was enjoyable and educational. It helped me understand why babies cry." While another father shared: "...helpful to first time parents like myself that need to learn how to cope with babies crying." A young 18 year old mother shared: "I believe this class will help a lot of first time mothers and fathers."

Theme: The Importance of Sharing with Others. This theme emerged depicts ways in which the participants viewed the content of the education class; and they expressed that the class was valuable and the class should be shared with other parents. Many of the participants offered suggestions for future venues of education classes. A young

father commented, "This program is very helpful and should be taken by every parent whether their baby is premature or not." The participants viewed the video/DVD as helpful and an important aspect of the class, as noted by one mother's comment: "The video and class needs to be shown to all parents and caregivers, daycares and schools. It really puts SBS into perspective on the dangers and outcomes it causes."

Several of the participants suggested the education class be a requirement for new parents to attend, as the information was educational and informative to first time parents and even for parents experiencing their second or third child. A first time father wrote: "Very informational, should be mandatory for all parents." While a 41 year old first time mother commented: "Good program, very unfortunate, should be required for all new parents."

Telephone Follow-up Results

A telephone follow-up survey was conducted 2 to 3 months after the parent or caregiver attended the education class. A majority of the participants, 94%, (N=31) had previously given permission on the questionnaire to be contacted and listed their telephone number for the follow-up. A random sample of 12 participants were contacted for the telephone follow-up. The results of the survey data showed that the participants continued to describe the strategies and interventions discussed in the class to be helpful. The participants identified several of the suggested coping strategies/interventions discussed in the class that they had enlisted, such as: checking to see if the infant's basic needs had been met, movement with the infant i.e. walking, rocking, swaddling, and listening to music. When no intervention or strategy worked, 8 out the12 participants

contacted reported they would put the infant down in a safe place and walk away and take a break for themselves and/or call a family member or friend for support.

The participants had all shared the various information that they received from the class with other individuals who cared for the baby or with other groups of people. Those individuals consisted of: their spouse, other family members such as the infant's siblings, grandparents, aunts and uncles. In addition, several of the participants reported they shared the information with babysitters, daycare providers, co-workers and friends.

One question on the telephone follow-up asked the participant what additional strategies/interventions had they enlisted in responding to their crying infant. While over half of those contacted listed they had used no additional strategies other than those discussed in class, over one third of the participants had used other helpful strategies. Those coping strategies consisted of positioning the infant in a particular way while being held or when placed in the crib, letting the infant feel the parent's breath, keeping the infant very close to the parent's chest, providing a double swaddle with two blankets or swaddling the infant prior to their anticipated time of crying (i.e. afternoon), watching the infant's cues and using a particular toy with the infant.

Response to the Statement of Commitment

At the end of each parent education class, the participants were asked to complete the questionnaire and sign the Statement of Commitment. The SOC was voluntary and was in non-carbon copies. Therefore, those who signed the SOC kept a copy for their records to serve as a visual reminder and the second copy was kept by the researcher. Of

the 33 participants in the study, 30 of them signed the SOC, showing the percentage of completion or participation at 91%.

Discussion

The purpose of this study was to determine the parent's and caregiver's perceived effectiveness of the educational class and to identify additional strategies the parent and caregiver found helpful in responding to infant crying. The 24 women and 9 men who participated in the study gave their time, attention, insight and shared their experiences during the education class; while 12 of them participated in the telephone follow-up.

Education on the dangers of shaking an infant and strategies to cope with infant crying are highly noted in the literature of SBS as recommended prevention measures. Showers (1992) discusses prevention of SBS begins with education of parents and other caregivers. Nakagawa & Conway (2004) advocate education is the key in the prevention of SBS by educating young parents and caretakers. They conclude aggressive education may hopefully reduce injuries and improve outcomes.

Several hospital based prevention programs have been documented in the literature. A recent successful program was in an eight county region of western New York. Dr. Mark Dias and colleagues (2005) implemented a hospital based, parent education program that targeted all parents of newborns at the time of the infant's birth. The results of this program showed the incidence of abusive head trauma decreased by 47% over a six year period. The program involved viewing an 11 minute video discussing the dangers of shaking an infant with suggestions to handle inconsolable infant crying. The parents were also given a one page leaflet on preventing SBS and were asked to sign a

voluntary commitment statement. The parents viewed the video and received the leaflet prior to discharge from the hospital (Dias, et al, 2005).

This present study was modeled somewhat in accordance with the successful hospital program mentioned above; however, this study looked at an education class on the prevention of SBS within a neonatal intensive care unit. The class was designed to educate parents and caregivers on how to calculate adjusted/corrected age for their baby, relating that information to the crying curve described by Brazelton (1962) and Barr (1990; Barr, et al, 1996). The class also provided further discussion, interaction with other parents of premature infants, provided education and information and distribution of brochures to the participants on coping with infant crying produced by the National Center on Shaken Baby Syndrome. The participants were also given a resource list with local and national contact telephone numbers they could utilize in the event the caregiver or parent needed someone to talk to during those bouts of frustration in coping with infant crying. The class provided a time for parents to share previous experiences in coping with inconsolable infant crying while networking with other parents and caregivers with hospitalized infants.

Although this study is somewhat different than Dias and colleagues (2005) hospital based prevention program, which provided a viewing of the video with supplemental literature, the findings of the current study further support the value of education on the dangers of SBS and coping with infant crying. It also provides some indication that education can have a beneficial effect on the implementation of preventative behaviors with parents and caregivers with their infants.

The findings of this current study do suggest that the educational class was perceived by the participants to be an effective teaching method against the dangers of SBS. The results from the questionnaire did validate that the parents and caregivers felt the class and DVD were helpful; the participants further noted the class would be helpful for other parents and the current participants planned to disseminate the information gained from the class with others who may care for their infant. Furthermore, the telephone follow-up indicated the participants did indeed share the information with others who cared for their infant. Also several participants provided suggestions and comments of additional strategies therefore; those results can be used as suggestions in future teaching of the education classes.

Study Limitations

Several limitations of this study were noted. The study was conducted in a metropolitan area with a small sample of participants. Therefore, the study lacks generalizability. Replication of the study with a larger population is recommended with the implementation of the program to encompass all aspects of newborn education with caregivers, not only in one hospital setting but perhaps all of the hospitals in a city or county. Another limitation is while the education class was developed in regard to prevention of SBS, it, did not track the incidence of a decrease in the reports of SBS. Such tracking would be essential to determine the ultimate effectiveness of a prevention program.

Implications for Occupational Therapy

SBS is devastating and disturbing but it is also preventable. Primary prevention efforts on the dangers of shaking an infant, anger management, and adaptive coping strategies are critically important components to include in the education of SBS. What typifies SBS is the parent or caregiver demonstrates difficulty in dealing with stress and poor impulse control during their occupational role of responding to infant crying. This study demonstrated one example of a prevention program addressing the occupational role of responding to infant crying and the dangers of SBS.

Historically, prevention programs within the profession of occupational therapy have addressed tertiary prevention at mainly individual levels. The role for occupational therapy in primary prevention is supported in several professional documents. Those include: the *Guide to Occupational Therapy Practice* (Moyers, 1999) and *Occupational Therapy in the Promotion of Health and Prevention* (Brownson & Scaffa, 2001). In addition, the *Occupational Therapy Practice Framework: Domain and Process* supports health promotion and prevention (AOTA, 2002).

The national document, *Healthy People 2010,* provides a comprehensive national health promotion and disease prevention plan and identifies 28 focus areas. Injury and violence prevention is listed as a focus area and *Healthy People 2010* encourages and promotes interdisciplinary efforts. While this study focused on a hospital based prevention program another prevention venue for occupational therapists is through community based intervention. In providing community based intervention and networking with community agencies, governmental agencies, and federal, state and local

prevention agencies, the therapist expands their role beyond traditional approaches to encompass primary prevention strategies. By networking and resourcing with other professionals in the campaign against SBS, the occupational therapist works in the role of a consultant, collaborator and contributor (Scaffa, et al, 2001). Occupational therapy brings valuable knowledge, insight and experience on participation and occupation to support the interdisciplinary efforts on the prevention of SBS.

Conclusions

This program evaluation of the parent's and caregiver's perceived effectiveness of a hospital based education class documented the class to be an effective method of conveying the dangers of SBS and strategies to cope with a crying infant. It is hoped that the findings from this study will provide the impetus to expand similar prevention programs on a larger scale. Although the results of SBS are irreversible, the opportunities for prevention and education of parents and caregivers are plentiful.

Table 1. *Demographics of Participants (N=33)*

Age	Data (in years)	
Age (n=33)		
Mean	30.78	
Range	18.0- 66.0	
Women Age (n=24)		
Mean	31.41	
Men Age (n=9)		
Mean	29.11	
Gender	Data	(%)
Gender (n=33)		
Women	24	(73)
Men	9	(27)
Mean Educational Level		
Some college	12	(36)
High school graduate	8	(24)
Post-college degree (Masters, PhD)	6	(18)
College graduate	4	(12)
Some high school	3	(9)
Relation	Data	(%)
Relation to infant as caregiver (n=33)		
Mother	20	(61)
Father	8	(24)
Grandmother	4	(12)
Uncle	1	(3)

CHAPTER IV

LISTENING TO THEIR VOICES:

PARENTS' PERSPECTIVES ON INFANT CRYING

Submitted for publication to Infant Mental Health Journal

But what am I?

An infant crying in the night

An infant crying for the light.

And with no language but a cry.

Alfred, Lord Tennyson

Introduction

The cries of infants have long been a topic of study for physicians, parents, professionals and scientists (Murry & Murry, 1980). Crying is considered a behavior, an acoustic, social but yet a communicative event which conveys information regarding the infant's basic needs and their nervous system (Lester, 1985). Crying is a normal part of infant behavior and development; it is the infant's way of communication. As Barr and colleagues note, crying is now understood to be a sign, as well as a symptom of a problematic function; crying is viewed as a signal in interactive contexts (Barr, Hopkins, & Green, 2000).

Crying in infancy is the earliest and one of the most compelling infant signals. (Barr, Konner, Bakeman & Adamson, 1991). Research over the last 50 years has revealed normal crying behavior does have a pattern. This predictable pattern is seen during the first year of life. Wessel and colleagues (Wessel, Cobb, Jackson, Harris & Detwiler, 1954) made reference to certain times of the day when infants would cry more; Brazelton (1962) also noted an infant crying curve from a study of 80 infants. Since then other studies have confirmed the earlier research and shown that the crying pattern of infants is characterized by an increase in crying at 2 weeks of age with the peak of crying seen at 6 to 8 weeks of age, then a gradual decrease in crying until 4 months (Hunziker & Barr, 1986; Barr, 1990). Other studies have shown preterm infants follow this same crying curve based on their corrected age (Barr, Chen, Hopkins, & Westra, 1996). In addition infant crying has a diurnal rhythm showing clustering in the late afternoon and early evening (Brazelton, 1962; Hunziker & Barr, 1986; Barr 1990).

Crying is the highest state of infant arousal. The rhythmical pattern of this robust crying is quite common to caregivers and parents. The cry of an infant may serve many purposes. The cry may be a result of pain and a way to communicate hunger, fatigue, discomfort or displeasure in being separated from their caregiver (Ludington-Hoe, Cong, & Hashemi, 2002). Researchers believe in the first few months of life, crying is a signal for attention (Barr, 2004). The purpose of the cry then develops into a feedback system between the infant and adult. The cry is a potent signal for the infant. The cry is designed to elicit a maternal response, with the response changing the infant's physiologic condition or to provide caregiving (Ludington-Hoe, et al.). When an infant

cries, the crying gets the attention of the parent, who in turn interacts with the infant to calm and soothe them, often times with the parent holding the infant (Barr, 2004). As stated by Barr (2004), "crying thus creates a process in which parents become attuned to and learn about their new infant" (p. 1).

However, in spite of its role in communication, excessive infant crying can be one of the most difficult aspects of parenthood (Long & Johnson, 2001). This same crying can often times cause the parent frustration and stress, provoke feelings of anger, guilt, despair, and significantly increase the risk of nonaccidental injury to the infant (Frodi, 1985; Crowe & Zeskind, 1992). Inconsolable crying is the major precipitating factor in Shaken Baby Syndrome (Nakagawa & Conway, 2004). The shaking typically results from tension and frustration generated by a baby's crying or irritability (American Academy of Pediatrics, 2001).

Purpose

Infant crying can pose a significant challenge for parents and caregivers, therefore the understanding of infant crying is important for professionals who work with infants and parents to help convey and reassure the parent that crying is a normal part of infant development and behavior. Understanding crying from a parent's actual perspective adds more insight and allows one to listen to their voice. The purpose of this qualitative study was to explore parents' perspectives on the lived experience of infant crying. The research questions were: 1) How do parents react to infant crying? 2) How does the parent cope with infant crying and what type of techniques or interventions do they use to

help with infant crying? 3) How is excessive crying or inconsolable crying described by the parent? 4) What time of the day does the infant cry?

Methods

Research Design

A phenomenological tradition was utilized for this qualitative inquiry. The rationale for choosing this tradition approach was to explore the parents' perspective of their feelings, perceptions and thoughts regarding infant crying and living with a crying infant. The phenomenological approach allows the researcher the opportunity to gather rich data by in-depth interviews with the parents who have directly experienced the phenomenon of infant crying. Participants in the study were asked to describe how infant crying affected their lives and how they adapt and cope with inconsolable infant crying. As Patton (2002) describes, "what is the meaning, structure and essence of the lived experience of this phenomenon for this person or group of people?" (p. 104).

Participants

Six parents were recruited to participate in this study. A convenience sample was used with recruitment occurring by word-of-mouth. Three females and 3 males participated. All participants were married, Caucasian and resided in a large metropolitan area in the Southwest United States. Approval for this study was obtained from a local university's Institutional Review Board.

The participant selection was limited to parents of a singleton infant, whose infant was between the ages of 6 weeks to 12 months of age. An equal sampling of both

mothers and fathers was represented. The preference was to interview only one parent of each household, either the father or mother, but not both.

The participants' ages ranged from 27 to 44 years of age ($M = 34.3$). The mothers ages ranged from 27 to 35 years of age ($M = 31.3$), while the fathers ages ranged from 33 to 44 years of age ($M = 37.3$). The participants had an infant whose age was between 8 weeks and 7 months of age (five months adjusted age) with the average age for the infant being 12.5 weeks old. The participants' number of children ranged from 1 to 2. This was their first child for two of the participants, while for the other four participants this was their second child. Of the participants' infants, five were full-term, while one infant was born 2 months early. None of the infants had any serious health problems nor did they have any serious health issues at birth. Demographics of the participants are contained in Table 1.

Data Collection

The participants were given both verbal and written information regarding the purpose of the study and informed consent was obtained. Data collection included a questionnaire and an individual, semi-structured interview with each participant. The questionnaire provided brief demographic information and questions addressing issues regarding their baby and the family, it was designed to be time efficient at the interview. For example a few questions asked specifics of the infant's age, sex, birth order, and health while other questions addressed specific crying patterns, who provided care for the infant, and how long the parent was home alone with their infant. The questionnaire was formatted similar to a questionnaire used by Long and Johnson (2001; 2006).

The interview questions were developed to target the subject of infant crying; and the emotions, feelings and thoughts provoked from infant crying were explored. All interviews were conducted in the participant's home. A single visit to each household occurred at a time convenient for the participant. The interviews contained open-ended questions and probes for more information. Following each interview, field notes were recorded to provide description and reflection. The field notes detailed the environment, descriptions of the participants, as well as the mood and demeanor of the participants. This further provided more context and reflection. The interview sessions varied in length from 45 minutes to approximately 2 hours, and were all audio taped.

Data Analysis

Each interview was audio taped, transcribed verbatim by an outside party, and then checked by the primary researcher for accuracy and anonymity of the participants. Pseudonyms were used during the interview process to allow for confidentiality of the participants. Data analysis occurred through thematic analysis. Each interview transcript was read multiple times and then open coding was used for identification. Three peer reviewers, with qualitative research experience, provided additional coding as this ensured credibility and trustworthiness. The coding was given conceptual labels and developed into systematic categories. Once these categories were clustered together they were further analyzed to uncover patterns or themes from the interviews.

Trustworthiness was established by triangulation, credibility and confirmability. Triangulation refers to a means of collecting information by using a variety of methods

and sources (Fielding & Fielding, 1986). Maxwell (2005) further defines triangulation as "strategy that reduces the risk that your conclusions will reflect only the systematic biases or limitations of a specific source or method, and allows you to gain a broader and more secure understanding of the issues you are investigating" (p. 94-95). For this study there were multiple sources of data, including the questionnaire, the interview transcripts, multiple coders, observations, and the field notes.

Credibility was ensured by member checking, as several of the participants were contacted for clarification and to ensure accuracy of the findings. As mentioned, a peer review was performed on all transcripts to demonstrate credibility and dependability. In regards to confirmability, an audit trial was provided by the transcribed audiotapes, the questionnaires and the field journal. Therefore, the peer reviewers were able to read the research and follow the researcher's logic and thought process of how the data were interpreted.

Results

Several themes emerged during the coding process; however, only three salient themes are described below. They include: longing for answers, heightened emotions, and coping strategies. Additional sub-themes were identified and are also presented, those include: description of excessive or inconsolable crying and pattern of crying episodes.

Themes

Longing for Answers. Initially the parents would often question what was wrong with the infant when the infant's crying was persistent, excessive or inconsolable. They

seemed to be attempting to find out the cause of the crying, and if so to alleviate the crying. One mother, Renee shared "its been a challenge at times when I've fed her or when I've burped her when she just constantly will continue crying and I don't know what's wrong with her, or why she umm, why she's not content." While a father, Les described his thoughts as "when there's a prolonged cry my first thought, is he sick, is there something wrong? Especially if you've tried, if you've tried to feed him or we continue to walk him." A first time father, Roy mentioned "I pretty much feel helpless. I try to figure out what's the matter or what's wrong with him or how to get him to stop crying." Erin described going through a process of elimination in her experience with her son during his early bouts of crying:

> I just wanted to know what I could do to, you know help him or whatever. Started thinking of things, okay is he fed? Okay is he wet? Okay. You know if he was, if he was fed and he was dry then I guess I felt…I guess a little fearful because then you think automatically that something must be wrong with him, you know.

In the parents' attempts to find out what was wrong with their infant, many reported they began to question themselves. They wondered if they had caused the crying or if the crying was a reflection upon their parenting skills. Renee remarked "It makes me try to figure out am I doing something wrong, is she uncomfortable? Feeling like what am I, what am I not doing for her that I should be doing?" Susy, a mother of two daughters, begin to question herself when respondiug to her daughter's crying episodes:

> At first I wondered was, what is going on is her tummy hurting? Have I been eating something wrong, because I was breastfeeding her, and she was spitting up a lot…Then with Natalie, I started thinking something, it was something I was doing wrong.

Overall, the parents conveyed their feelings as if they were searching for something to explain or define what was wrong with their infant to cause the crying or if they themselves were to blame for the infant's crying.

Heightened Emotions. The parents consistently expressed multiple feelings and thoughts they experienced in response to their infant's inconsolable crying. The participants described feelings of frustration, anger, sadness, helplessness, stress, isolation, guilt, depression and a sense of being overwhelmed. Roy, a father of a 9 week old, described one crying bout as a sense of feeling helpless and just wanted his son to give them a break. Renee, a mother of two, described her thoughts on her daughter's crying and how she too would find herself crying as well:

> I was obviously very saddened, again. I think my hormones were just taking the best of me, I cried a lot. You know and that's the other thing when I talked to my doctor, I started thinking I was going through postpartum depression because I would get frustrated and angry that I could not find ways to soothe her and calm her down, when we did not have this much difficulty with my son…It was hard for me but I, I tried to just do what I could to, to keep her calm. But for me, I was, you know I went through periods of sadness and crying

and anger and frustration because I just was, at my wit's end, and I didn't know what else to do!

Often times the parent felt guilty in addition to their frustration, stress and anger because they spent a great deal of time consoling their crying infant. They felt guilty not spending time with the older child in the house or did not want the crying to upset their other child. Les, a father of two, expressed:

> It is more a feeling of frustration…One frustration when he cries like that is, we're afraid he is going to wake this one [sister] up. And then we'll have two, and he has done that before, he's awoken her at least once with his crying and then we've got two crying kids.

Erin shared her thoughts in managing her two year old daughter while struggling to comfort her son's crying:

> I feel like I'm going to cry. I haven't ever cried yet but I do feel as though I'm on the verge of crying. Especially when my two year old's wanting the same attention. I get umm frustrated and sometimes angry not necessarily like angry at him but I'll get even kind of a little bit frustrated towards my two year old who's trying to talk to me in the midst of him crying in my ear after an hour or two. Then I'm like Jaelynn [older sister] I'm trying to, you know deal with this….then I'll think, I've been holding him for an hour and a half and she's just trying to be a two year old to help me, you know?

Some of the parents reported a heightening of their feelings in response to their infant's inconsolable crying. The parents would not necessarily express anger towards the child per se but have anger and frustration at the situation as their emotions would heighten or escalate as the crying continued to persist. Michael, a first time father, who worked from home, summed up his emotions in this progression:

> Well, it's just absolute frustration really, and then aggravation...Maybe I'd rock a little faster, something to see if anything would, would absolutely work. But for the most part it's just really umm agitation and frustration which then leads to aggravation which then leads to anger.

Several factors led to a feeling of being isolated within their home. With the attempts to soothe the crying consuming all of their time and energy it often at times consumed their emotions. Natalie cried excessively everyday from around 5 pm to 11 o'clock at night for weeks straight, her mother recalled the following:

> I would get very angry. Not angry at the child, not angry at Natalie and not angry at Sophia [older sister], just mad because I couldn't get anything done. I could not do anything. I couldn't take a shower, I couldn't go anywhere, I couldn't clean the house. I couldn't do anything because she would cry all the time. If I put her down she'd continue to cry...I almost feel like a prisoner in my house. Now how much of that is crying and all her? How much of it is having two kids, within 16 months and then very isolated. We couldn't go out to eat anymore, we couldn't go do anything.

These experiences described by the participants show a few examples their frustration, anger, stress, fatigue and even changes in their families' lives in responding to and handling their infant's bouts of inconsolable crying. These emotions also led the parents to find ways to cope with the crying.

Coping Strategies. It was evident that the parents enlisted various coping strategies in response to inconsolable crying. The parents described their strategies in an attempt to comfort and soothe their baby; they also described how they utilized coping strategies in response to the crying. In the majority of responses, the parent would describe their first response to the crying by picking up the infant and holding them close to their body. The parents identified many coping strategies like holding the infant in a particular way, using auditory responses – such as playing music, singing, or talking to their infant and using the sounds of appliances to help soothe the crying. Other coping strategies included swaddling, taking the infant outside or some form of a change of environment, and giving the infant a warm bath. Often times if their spouse was home, the parents reported handing the infant off to their spouse when they needed a break from the crying. Another consistent coping response the parents reported was simply holding the infant and sitting with them on the couch or in a chair for extended periods of time. Susy described the following:

> My husband would come home from work and I would just be a basket case. I would just be sitting on the couch holding her because I had finally gotten her to stop crying. If I moved, she would cry again.

The most repeated response the parents described was some form of movement, whether it be walking, rocking, bouncing, swaying the infant or placing them in a swing. Roy described how he would first pick-up his son to comfort him and then walk around while holding him and pat him on the back or bounce with his son on an exercise ball. Erin discusses how she held her infant and moved with him in an effort to console the crying:

> I pick him up and I put him close to me. Usually always sideways then I put the pacifier in his mouth and I push him up against me with his head kind of up against me and I, I bounce him…if that doesn't work I stand up and…do a rocking swing motion…You know I haven't been able to put him down as much. I've had to hold him a lot more. You know I tend to put maybe even, even going to the bathroom with him in a car seat, rocking him [the car seat] back and forth just because he will just cry, cry, cry, cry, and cry.

The parents recounted some of their most difficult episodes of coping were when they would have to put their infant down in a safe place and physically walk away, allowing themselves a break, breather, a time to regroup or time away from their infant. Typically this type of coping response occurred when the parent was caring for the infant alone at home with no immediate support from their spouse or another family member. Michael comments on an incident were he had tried everything, but eventually had to walk away from the crying:

> A couple of weeks ago I tried to feed him, he wouldn't take a bottle, I tried playing with him, that wouldn't work. I tried rocking him, that wouldn't

work. I'd put him down for a little bit and he'd keep fussing...there just wasn't anything that I-I seemed to do that would, you know that would stop him... For my sanity's sake I'd just had to put him in his crib and walk away and kind of give myself a little time out to kind of get my breath.

While another time Michael described how he personally relieved his frustration when his son's crying was so overwhelming:

I've got a boxing dummy that I keep in the garage. One time I actually had to got out there and I put him down because I couldn't get him to sleep, I couldn't get him to do anything. So then I was just getting so frustrated I didn't know what else to do so ah, I just put him down and I, and I went out and put on the, the boxing gloves. Aud I kind of had some, some you know some punches just to kind of get out some anger and frustration and all that sort of stuff and then kind of calmed down. Then I, you know regrouped and came back and you know and tried it again.

The attempts to find respite relief from the spouse in regards to the crying were often filled with a feeling of guilt. Susy describes a few instances where her husband made her leave the home to take a break for herself.

...One time I mean I just drove. I didn't even have a goal in mind, I just drove until I saw somewhere I thought I'll go in there and each time was for about an hour...but I felt guilty. I felt I should be home, taking care of, the baby and my other baby and I didn't want my husband to be going through the crying.

> Like I had been going through the crying. Cause he had been working and I-I would feel like that's just my responsibility as the mother.

Renee conveyed how many times she felt isolated and confined to her home and several times felt "like the walls were caving in." She recounts several incidents where she had to leave her house.

> I got to the point where when my husband would come home from work I would say, "Here. Here you go." Give her to him, and I would just go up to the grocery store or I'd go put gas in my car…Just get away for even that short 15, 20 minute break or walk around the block. Because I literally, I got to the point where I did feel like everything was caving in, I was about to pull my hair out and I needed, I needed a break.

Overall, the parents described many different strategies, however all of the parents mentioned that not one particular strategy consistently brought relief. Many times the parent would offer various coping and soothing techniques but in the end, the crying still continued for hours.

Sub-Themes

Two additional sub-themes of significance emerged from the study, those were: description of excessive or inconsolable crying and pattern of crying episodes.

Description of Excessive or Inconsolable Crying. The participants expressed this type of crying to be very loud, grating and a constant and persistent cry. One father mentioned: "They continue to cry even when you feed them, rock them or walk with them, it doesn't stop." Other descriptions of inconsolable crying referred to their baby

looking anxious and having a helpless look in their eyes. Overall, the parents reported nothing helped to soothe these bouts of excessive crying; despite multiple attempts, nothing they did would stop the crying or it only stopped momentarily. One mother summed up her understanding of inconsolable crying as: "Something is going on in her brain that makes her feel like she just needs to cry, just because she needs to cry."

Pattern of Crying Episodes. The other sub-theme identified was the consistent description of the infant crying episodes to be in the afternoon or evening time. The parents reported these crying episodes began around 3 pm and often times would go until 12 midnight. Renee reported that her pediatrician encouraged her to keep a log of her daughter's crying and noted: "It was really more or less between 6 pm to almost 12 pm straight of nonstop crying. It was every night…probably a good three to four weeks straight."

These two sub-themes denote and support the research questions of how the parent's define what time of the day the infant may cry and how they describe excessive crying or inconsolable crying.

Discussion

The purpose of this qualitative study was to explore parents' perspectives on the lived experience of infant crying. The 6 men and women who participated in the study gave their time, attention, insight and shared their experiences of living with infant crying. The mothers and fathers described their feelings, emotions, thoughts and actions in response to coping with infant crying.

The themes described in the Results section support and correspond to the research questions as do the additional sub-themes addressed in the end of the Results section. The theme of longing for answers described how the parent sought to find out why the infant was crying and searched for answers to the explain the inconsolable crying. While the theme of heightened emotions demonstrates the parent's true expressions of living with infant crying and describe not only their emotions, thoughts and feelings but also their reaction to infant crying.

One interesting pattern reflected by the majority of the responses from the parents, was the type of strategies they enlisted in attempts to soothe the crying. These strategies followed the same soothing categories described by Barr (2004). He suggested six different techniques: swaddling, movement, touch, sounds, warmth, and something different – a distraction (Barr, 2004). The most reported techniques that participants described involved some form of movement. The most often cited type of movement was walking with the infant or holding them close and rocking, swaying, patting or gently bouncing with them. Although this strategy did not consistently remedy the crying, it appeared to be the most consistent and enlisted type of strategy or technique reported.

An important point that emerged from the study was the consistent description of the infant's crying episodes to be in the afternoon or evening time. This afternoon and evening pattern reported by the participants concurs with the pattern described in the literature of a diurnal rhythm, with typical clustering of crying in the evening hours (Brazelton, 1962; Hunziker & Barr, 1986; Barr, 1990).

Study Limitations

Several limitations of this study were noted. The study was conducted with a small group of participants and only one ethnic or racial group was represented (Caucasian). In terms of the family dynamics, none of the participants were single parents; all were married and had, to some extent, a support system of their spouse and in several cases other family members to call upon. The majority of the participants were in young adulthood; perhaps a more diverse age group including late teen years and early twenties would yield even more perspectives. The findings of this study can not be generalized but do reveal the meaning of the participants' real-life experiences related to the phenomenon of infant crying. This study was designed to provide a description of the parents' perceptions of infant crying and to allow a greater and deeper understanding of their thoughts, feelings and behaviors when responding to infant crying.

Clinical Implications

Understanding infant crying is a critical component for professionals who work with infants and parents. It is important to convey and reassure the parent crying is a normal part of infant development and behavior. However, it is equally important to understand, listen and validate the parent's feelings and emotions that they are experiencing in coping with infant crying. This may be done by providing a support system or network of professionals, parents and other caregivers for parents to discuss their feelings and offer encouragement and reassurance. It is essential professionals be attuned to parents' responses to infant crying. Education and primary prevention efforts that include understanding infant crying, the dangers of shaking an infant and adaptive coping

strategies for parents and caregivers are important. Since crying is the precipitating factor in cases of Shaken baby Syndrome (Nakagawa & Conway, 2004).

In conclusion, this study was exploratory in nature examining parents' perspectives of their feelings, perceptions and thoughts regarding infant crying and living with a crying infant. It is hoped that other professionals will find these results to be helpful and perhaps enhance their intervention with infants and parents. It is also encouraging that further studies into exploring the topic of parents' perspectives will ensure that we do "Listen to their voices".

Table 2. – *Participant Demographics*

Name	Age of Parents	Age of Infants	Sex of Infant	Sibling Order
Susy	35	4.5 months	Female	2nd
Roy	33	9 weeks	Male	1st
Renee	32	11 weeks	Female	2nd
Michael	35	7 months (5 months adjusted)	Male	1st
Erin	27	9 weeks	Male	2nd
Les	44	8 weeks	Male	2nd

CHAPTER V

EXPLORING CO-OCCUPATIONS: PARENTS' RESPONSES TO INFANT CRYING

Submitted for publication to Occupational Therapy Journal of Research

Hush little baby, don't you cry

Within your dreams, you can touch the sky

With you in my arms, I feel whole

Because you are, my heart and my soul

British Lullaby, Author Unknown

Introduction

For parents, the first cry of an infant at birth is a joyful, emotional and an expressive event that announces their new child into the world. An infant's cry is one of the earliest and most compelling infant signals (Barr, Konner, Bakeman, & Adamson, 1991). The piercing sound of an infant's cry can elicit a multitude of responses, behaviors and emotions from the parent. This crying is a normal part of infant development. Crying is a behavior and the primary mode for the neonate and young infant; to express and communicate their basic needs (Lester, 1985).

Crying is able to elicit a strong emotional response from the parent, which may affect parent-infant interactions (Lester, 1985). However, excessive infant crying can be one of the most challenging aspects of parenthood (Long & Johnson, 2001). This excessive or inconsolable crying can lead to a deadly form of child abuse called Shaken Baby Syndrome (SBS). Inconsolable infant crying is the precipitating factor of shaking an infant (Nakagawa & Conway, 2004). However, it is a preventable tragedy.

Infant Crying

Newborns tend to have many vocal sounds; however, parents pay most attention to the crying. Parents may be more attuned to the sound of possible distress, and the sound of crying can be disturbing (Small, 1998). Crying is the basic form of communication for the infant, and it is a normal part of infant behavior and development. Research studies over the past 50 years have shown normal crying does have a predictable pattern. In the 1950's, Wessel and colleagues (Wessell, Cobb, Jackson, Harris & Detwiler, 1954) noted certain times of the day when infants would cry more. Brazelton (1962) conducted a study of 80 infants and noted an infant crying curve. Other studies have replicated this earlier research and confirmed that the crying pattern of infants is characterized by an increase in crying at 2 weeks of age with the peak crying seen at 6 to 8 weeks of age, then a gradual decrease until 4 months (Hunziker, & Barr, 1986; Barr, 1990). Infant crying shows a diurnal rhythm of crying clustered in the late afternoon and evening (Brazelton, 1962; Huniker & Barr, 1986; Barr, 1990). Also, preterm infant studies have shown this same type of crying curve based on the infant's adjusted age (Barr, Chen, Hopkins, & Westra, 1996).

The cries of infants may serve many purposes, and researchers note the first few months of life crying is a signal for attention (Barr, 2004). The infant's cry is designed to engage a maternal response, and the response changes the infant's physiologic condition or triggers a caregiving role (Ludington-Hoe, Cong, & Hashemi, 2002). In summary, the purpose of infant crying is to obtain the attention of the parent who then interacts with the infant to soothe and calm the child, and in many cases, by the parent holding the infant (Barr, 2004).

Shaken Baby Syndrome

SBS is a deadly form of child abuse. The National Center for Shaken Baby Syndrome (2005) reports approximately 1,400 cases of SBS occur each year, while 25% to 30% of these victims die as a result of shaking. This abuse occurs when an adult caregiver violently shakes an infant or small child. According to Nakagawa & Conway (2004) the physical characteristics of SBS are: intracranial bleeding, cerebral edema and retinal hemorrhages resulting from repetitive acceleration, deceleration, and rotational forces. The results of these injuries may cause severe neurological impairment or even death for these tiny victims.

Typically the victims of SBS are less than 1 year of age with the peak incidence occurring between 6 weeks and 6 months of age, with boys affected slightly more than girls (Nakagawa & Conway). The perpetrators can be anyone, such as: mothers, fathers, baby-sitters, grandparents, day-care workers; or any individual with adult strength is capable of shaking an infant. Males are responsible for 60 to 70% of all reported cases of SBS (Butler, 1995; Lazoritz, Baldwin & Kini, 1997). Reports of shaking baby cases note

that the adult was unable to control their frustration and anger and shook the infant in an attempt to stop the crying (Castigila, 2001).

Occupational therapy has many opportunities to contribute to the primary prevention of SBS. Hundreds of occupational therapists interact and provide client-centered care on a daily basis with parents and children and, therefore, are in an excellent position to be advocates to develop and establish primary prevention programs. Scaffa and colleagues (2001) note occupational therapy has a rich potential to have an impact in the area of injury prevention especially because of our unique contribution on the perspectives of occupation and occupational science.

Because of this unique understanding of occupations, occupational therapists are in a position to further explore and understand one aspect of the occupational role of parenting, in this case, the parent's response to infant crying. Llewellyn (1994) notes occupational therapy is well placed to further explore parenting from a participant perspective. In describing the occupational role of responding to infant crying, it is important to acknowledge the co-occupations of caregiving. Activities that are considered co-occupations require more than one person's involvement; for instance, the caregiving of an infant, involves both the parent and the child (Zemke & Clark, 1996). Olson (2004) states there are actually two actors for every occupation of caregiving. An example of a co-occupation of caregiving would be feeding; the parent prepares the infant's bottle and feeds the infant, the infant in turn performs the task of eating and also has their need of hunger satisfied (Olson). Researchers believe in the first months of life, infant crying is a signal for attention (Barr, 2004). The purpose of the cry then develops into a feedback

system between the infant and adult. As the parent attempts to comfort and respond to infant crying, the response of comforting the infant is considered a co-occupation. The crying requires some type of a response from the parent and the infant, in turn, is expressing a sign, signal or even a symptom of a problem (Barr, Hopkins, & Green, 2000) to elicit a response from the parent. The interaction of a co-occupation, then, occurs between them.

In cases of SBS, the parent or caregiver demonstrates difficulty in dealing with stress and poor impulse control during their occupational role of responding to infant crying. Crying exerts a powerful influence on the family and greatly increases the risk of nonaccidental injury to the infant as the crying provokes feelings of anger, frustration, stress, and guilt for the parent (Frodi, 1985; Crowe & Zeskind, 1992). Therefore, as therapists, it is important to listen, acknowledge, and explore the parent's feelings, actions and strategies enlisted when responding to their infant crying.

Purpose

This study was part of an ongoing line of research of exploring parents' perspectives and behaviors in regard to infant crying. The purpose of this study was to glean behaviors, actions and emotions in which the parents engaged when responding to infant crying. The research questions were as follows:

1) What was the parent's behavior when their infant was crying?

2) What are the types of activities in which the parent engaged in when responding to their crying infant?

3) How did the parent describe their feelings when responding to infant crying?

Methods

Research Design

An ethnographic method was used for this qualitative study, exploring the culture of parental caregiving of an infant. The rationale for choosing this tradition approach provided an exploration and observation of the parent's behaviors, actions and emotions regarding infant crying in their home context. Participant observations provided the researcher the opportunity to see what the parent was experiencing and, to some extent, allowed the researcher to vicariously experience the phenomenon, of the parent response to infant crying. Participant observations provide the researcher the opportunity to uncover and reveal the meanings people use to make sense out of their daily lives (Jorgensen, 1989).

Participants

Four parents were recruited from a previous study to participate in this study. A convenience sample was used with recruitment of the participants occurring by word-of mouth. Two males and 2 females participated; all participants were married, Caucasian and resided in a metropolitan area in the southwest region of the United States. The approval for this study was obtained from a local university's Institutional Review Board.

The selection of the participants was limited to parents of a singleton infant, whose infant was between the ages of 6 weeks and 12 months of age. Equal sampling of both mothers and fathers was represented. All participants were from different households; the preference was to interview either the father or mother of the household, but not both.

The age of the participants ranged from 27 to 44 years of age (M = 34.75). The range of the mothers' ages were from 27 to 35 years (M = 31), while the fathers range was 33 to 44 years of age (M = 38.5). The infant ages were between 8 weeks and 4.5 months of age with the average age of the infant being 11 weeks old. For one parent this was their first child, while for the others this was their second child. All of the infants were full-term and none of the infants had any serious health problems at birth nor did they currently have any health issues.

Data Collection

A total of 7 observations were performed with the participants. All of the observations took place in the home of each participant. The participants were given both verbal and written information in regard to the purpose of the study and informed consent was obtained. Data collection included information obtained via a questionnaire (Long & Johnson, 2001; 2006). The questionnaire contained brief demographic information and questions' regarding their family, the infant's age and other questions about their infant's crying patterns. During the observations a participant observation grid was utilized to format and record the participant's activities in which they engaged. The majority of the observations occurred in the afternoon or evening time, as this is the period of time when most infants tend to demonstrate an increased period of crying. Overall, the observations depended upon the availability and flexibility of each participant. Three of the participants were observed twice while one participant was observed one time, making a total of 7 participant observations. Each observation lasted from 1 to 2 hours. The parent was encouraged to go about their daily routine as much as

possible during the observations. The observations included the parent performing typical child care activities, such as feeding, playing with the child, providing other types of child care as well as observing the parent soothe and comfort the infant during crying episodes.

The information obtained during the observation was then transcribed verbatim. Extensive field notes were kept of each observation to document not only the participant's behavior but also the researcher's behavior and experience in the field, allowing the researcher a time to reflect on her thoughts and feelings of each individual observation.

Data Analysis

The field notes and the observation grids were transcribed verbatim to allow for analysis. The field notes contained a detailed and in depth description of the observation, identifying the place, the purpose, the setting, the people and the actions during the observation. Pseudonyms were used during the observation process to allow for confidentiality of the participants. A description of the physical environment was described by a basic floor plan to recount the data.

The field notes and observations were read numerous times and then organized into readable narrative with major themes, categories; case examples were identified through content analysis (Patton, 2002).

Peer review was utilized to demonstrate credibility and dependability. A peer reviewer, with qualitative research experience, provided review of the observation grids and the coding process. Member checking also ensured credibility as some of the

participants were contacted for clarification and to ensure accuracy of the findings. Confirmability was obtained by providing an audit trial from the questionnaire, field notes and observation grids. This allowed a record of the researcher's logic and thought process of the data for the peer reviewer.

Results

The data were analyzed and multiple patterns or themes emerged as the parents were observed demonstrating how they responded to infant crying. Many themes emerged; however, only the salient ones are described here: immediate response to crying; routines; and utilizing movement as a coping strategy.

Themes

Immediate Response to Crying. All the participants were observed to immediately pick up their infant as their first response to the crying. It was as if an instinct or a natural response to the crying. Often the parents described this as an automatic response to help soothe the crying, before the crying further developed, and provide direct physical contact with their infant. Many times this was then proceeded by the parent checking to see if the infant's basic needs had been met and going through a checklist: are they hungry, does their diaper need to be changed, do they need to be burped, are they cold or in pain for some reason? However, the initial response consistently was to hold their infant and comfort them. The parent also noted they initially wanted to find out the cause for the crying, searching for a sign or symptom that might denote why the infant was crying.

Roy, a first time father with a 9 week old son, was playing on the floor in the living room with his son. For no explained reason, Troy begin to cry, immediately his father picked him up, "Shoo" he said and held Troy close in a chest to chest position and gently moved his son back and forth, while repeatedly saying, "Shoo" and talking to comfort and reassure his son.

While talking with Les, a father of two, he demonstrated and described his initial response to pick up his 8 week old son and hold him very close in a particular manner to comfort the crying.

Les was sitting in a chair in his living room, holding his son Ryan while talking to me. His two and half year old daughter was parading around in the living room with her "Barbie" slippers on. Ryan begin to whimper and cry, his father changed his handling position and shifted Ryan to a more horizontal position and laid his son in the crook of his arm, as if to create a nest to cradle his son. After several minutes of holding his son in this position, the crying persisted. Les than reclined in the chair and laid Ryan on his chest, partially on Les's chest and shoulder and continued to pat and comfort his son to cope with his crying.

Erin and I were sitting in her living room, talking about her son Jeremy while he was resting in his bouncy seat. Jeremy began to cry and then Erin responded in this manner:

"In general I just go and pick him up." She picks her son up out of the infant seat, and puts him very close to her. She holds him in a diagonal across her chest and stomach, with Jeremy turned sideways towards her body. She then gives her son a pacifier and pushes him firmly up against her with his head

against her firmly and then she bounces and sways with him. Erin comments, "If that doesn't work, uhm, sometimes…I stand up and do this." She then rocks and sways her son in her arms in a side to side position.

In their first response to crying, all the participants picked up and held their infant. In most instances, the parent performed the activity of picking up and holding their infant in an instinctive manner while still continuing their conversation with the observer.

Routines. The participants described and demonstrated what they defined as a routine or a consistent way in which they responded when comforting or attempting to calm their crying infant. One mother was observed preparing her children for a typical afternoon nap. However, the mother noted that often times this normal occurrence for most children of an afternoon nap became a common occurrence of questioning if her daughter would cease the crying and take a nap. Would her daughter cry relentlessly instead of napping and how the consistent crying produced emotions of frustration, guilt and stress for her, as the mother?

> A typical afternoon for 4 month old Natalie consists of nap, but often times the nap is preceded or even replaced by crying. This is a very common occurrence or routine for Susy, a mother of two girls. Susy changes Natalie's diaper amidst all of the crying, then gently snuggles her daughter close to her chest and sits and rocks in the rocker attempting to soothe the crying. As Natalie cries and cries, her 21 month old sister, Sophia says: "Shoo" and leans over and kisses her baby sister. Despite the sister comforting her and her mother holding her tight and rocking her, Natalie continues to cry. Soon not only Natalie is

crying but her older sister is crying as well. Now there are two crying children and one exhausted mother. Susy comments: "It gets frantie with two crying. I take it; it is my responsibility to get her to sleep, to stop crying."

Throughout the observations, the parents would comment on a particular routine of strategies in which they engaged while attempting to soothe the crying. One mother described her feelings of frustration, anger and a sense of being overwhelmed when her young infant son had his long, inconsolable bouts of crying. She referred to a fairly consistent routine in which she would utilize her car seat to help reduce the crying.

Erin, a mother of 2 small children, recounted a time when her 9 week old son was wailing one evening about the time she needed to leave their home. She placed and buckled up her son in the car seat. As she began driving, she noticed the crying stopped, and on several other occasions, her son ceased his crying when placed in the car seat. Erin described several instances where upon returning back home, she and her husband would remove the car seat from their car, while Jeremy continued to sleep in the car seat. Then quietly they would bring their son into their house and leave him in the car seat to finish his nap. Often times throughout the day or evening, when Jeremy had his bouts of inconsolable crying, Erin would place him in the car seat at home and rock the seat back and forth. Erin commented: "In general it works to use the car seat. He sleeps better in it and tends not to wake up as much...when I put him in the car seat, I can rock him and it kind of just keeps him soothed."

On some occasions these routines helped soothe the crying. Whether or not these routines were always successful for the parent, they, at least, were a consistent attempt to stop the crying. As one mother said: "I try everything, until I run out of options."

Utilizing Movement as a Coping Strategy. The participants demonstrated and described various coping strategies they utilized in response to inconsolable crying. They were observed performing many coping strategies: using auditory responses of singing, playing music or talking to their infant. Other coping strategies included swaddling, walking into a different room with the infant and playing with the infant. During some of the observations, the parent handed the infant off to their spouse when they required a break from the crying. However, the most consistent strategy always involved some form of movement with the child. Whether that be walking, bouncing, patting the infant, or rocking the infant in some manner.

> While playing with his son, Roy quickly noticed Troy was beginning to get fussy and starting to cry. He immediately picked up Troy and held him to his chest and slightly bounced him up and down, then Roy sat on a exercise ball and held Troy in a fact to face position and bounced with his son on the exercise ball to alleviate the crying.

Les described one of the best strategies that he utilized was walking around the house while cuddling his son; walking back and forth while gently rocking his son in his arms was an attempt to soothe the crying. Another parent was observed providing another form of movement in an attempt to get her daughter to calm down to take a nap.

> Susy and I were downstairs in the kitchen, as she lives in a two-story home,

and her daughter's rooms are upstairs. You could still hear her 4 month old Natalie continuing to cry over the baby monitor. Interesting, as we walked up to stairs to the child's room, Susy mentioned that her daughter could hear noise of someone coming up the stairs and would momentarily stop the crying. As we entered Natalie's room, her mother went over to her crib and began talking to her. Susy picked up her daughter and immediately calmed her crying as by holding her very close to her in an upright position with direct contact to her face and chest and saying "Shoo." She then rocked and bounced the baby while walking around the room. After about 5 minutes of calming her, Susy laid Natalie back down in her crib, and Natalie showed changes in her facial expression of an anxious look as her mother talked and patted Natalie's chest. As we left the room, the infant began to resume her crying, and Susy talked about how difficult coping with her daughter's inconsolable crying had been and commented: "Last night when she was having a bout of crying, I thought, there is no way I can have another child, no way."

Overall, the parents engaged in many coping strategies to alleviate the crying but mentioned that not one particular strategy seemed to consistently bring relief to the crying. The parents verbalized they often had feelings of frustration, helplessness, anger, depression, stress, guilt, isolation, fear and discouragement in response to their infants' inconsolable crying.

Discussion

The aim of the current study was to glean behaviors, actions and emotions of the parents in response to infant crying. The 4 parents who participated in the study gave their time, insight, shared their experiences of living with infant crying, and allowed an outside party to come into their home to observe their interactions with their infant. The mothers and fathers openly demonstrated their behaviors and actions and shared their emotions and feelings during these observations.

The themes described in the Results section address the research questions as the parents either demonstrated, during the observations or described their behavior, actions and feelings in response to infant crying. An interesting pattern by the majority of the parents was noted by the type of strategies they enlisted in attempting to soothe the crying. The strategies the parents reported followed the same soothing categories described by Barr (2004). Those include six different techniques: swaddling, movement, touch, sounds, warmth, and something different, such as a distraction (Barr, 2004). The most reported type of movement to help comfort the infant was walking with their infant while gently swaying or bouncing the infant in their arms.

A notable finding of this research was several of the participant observations actually observed the emotions the parent experienced when the infant had inconsolable crying. This proved to be beneficial and enlightening as it allowed the researcher to see the frustration, fatigue, stress, concern, helplessness, aggravation and/or exhaustion the parent experienced when their child demonstrated an episode of inconsolable or

excessive crying. This provided insight into how the parents actually feel and manage their emotions in response to infant crying.

The value of the participant observations within the home context provided perhaps a truer and real experience of the parent's experiences. The use of participant observations fits well within occupational therapy of examining and exploring contexts. As Spencer (2003) addressed the occupational therapy practice framework (AOTA, 2002) denotes contexts as sources of facilitators or barriers to one's performance in areas of occupation and indicates that contexts do have a powerful influence on occupational engagement.

Study Limitations

Limitations that have been identified within this study are the small sample size of only 4 participants and a limited number of observations with the participants. The study was conducted with only one ethnic or racial group represented (Caucasian) and all of the participants were married and had to some extent other family members to provide a support system versus having a sample including single parents. The findings of this qualitative study can not be generalized but do reveal the meaning of real-life experiences in regard to responses to infant crying.

Conclusions

This study was part of a line of research of exploring parent perspectives and adaptation to Shaken Baby Syndrome. The precipitating factor of this abuse is inconsolable infant crying. This study addressed one question in this broader line of

research: what were the parents' behaviors, actions and emotions when responding to infant crying?

It is hoped that the results of these participant observations will provide additional information to further enhance our prevention strategies with SBS. One avenue is in regard to parent education, by acknowledging with the parent that their feelings are real and valid and they may experience frustration, anger, aggravation, isolation and other emotions in coping with inconsolable infant crying. This education could be provided in community based support groups, home health visits or early childhood intervention programs after the infant is born. Other areas are parent education classes in the hospital prior to discharge after the birth of the infant or in childbirth classes prior to the birth of the child. Various opportunities exist for occupational therapists to engage and contribute to the primary prevention of SBS.

Future studies concerning the parents' perspective on infant crying are encouraged. Further research into examining the co-occupations of parenting, more specifically, the response to infant crying will allow our profession to explore the meaning, values and intentionality of parenting (Llewellyn, 1994). As occupational therapists, we bring valuable knowledge, insight and experience on participation and occupation to support our efforts of collaborating, consulting and contributing to the prevention of SBS. It is hoped that the findings of this study will assist or support interest to establish or expand primary prevention programs. The results of SBS are irreversible; however, the opportunities for prevention and education of parents and caregivers are plentiful.

Perhaps these prevention programs, simply stated, will make a difference in saving the life of an innocent child.

CHAPTER VI

CONCLUSIONS AND IMPLICATIONS

The purpose of this dissertation was to examine from an occupational therapy perspective current prevention strategies of Shaken Baby Syndrome and to explore adaptive strategies used by parents in response to inconsolable infant crying. Infant crying is the major precipitating factor that causes an adult to violently shake an infant or small child. This dissertation consisting of three studies focused on parent education of infant crying and explored how parents adapt and handle inconsolable infant crying.

Several key findings emerged from this line of research. This chapter presents: a summary of the significant findings of each research study; the relationship of the findings to the occupational adaptation frame of reference; implications for occupational therapy; future research; research limitations; and the research process and conclusions.

Significant Findings

The significant findings related to the three research studies are summarized in this section along with each study's specific aim and corresponding research questions. The first study (Chapter 3) utilized a program evaluation design to determine the parent and/or caregiver's perceived effectiveness of an educational class and to identify additional strategies that the parents and caregivers found helpful in responding to a crying infant. A parent education class on infant crying and the dangers of SBS was established to provide primary prevention for parents and caregivers who had infants in

the NICU. The research questions were:

1) How did the content of the education class address the topic of parents/caregivers dealing with infant crying and to what extent did the participants find the class informative of the dangers of SBS?

2) How likely would the participants share this information with others who care for their child?

3) How have the participants enlisted any strategies and/or information they acquired in the class in responding to their crying infant and what additional strategies if any have the participant's developed in responding to their crying infant?

4) What percentage of the participants completed the Statement of Commitment?

The findings from this program evaluation were obtained from a questionnaire and follow-up telephone survey completed by the participants. All of the participants (N=33) perceived the class to be an effective method of addressing infant crying and conveying the dangers of SBS. The participants agreed that the education class was helpful, and they planned to share the information from the class with others who care for their infant.

The open ended responses on the questionnaire were analyzed with the two following themes supporting the benefits of the education class: helpful and informative class and the importance of sharing with others.

The telephone follow-up survey was performed with a random sample of 12 participants, with the results noting the participants continued to describe the strategies and interventions discussed in the class to be helpful. The participants reported they had shared the information from the class with other individuals who cared for their baby.

The participants also reported they had utilized several of the suggested coping strategies/interventions discussed in the class and several of the participants provided additional strategies/interventions they enlisted when responding to their crying infant. Those coping strategies consisted: of positioning the infant in a particular position while being held or when placed in the crib, allowing the infant to feel the parent's breath, keeping the infant in a close and tight-chest-to chest position, providing a double swaddle with two blankets or swaddling the infant prior to their anticipated time of crying (i.e. afternoon), watching the infant's cues and using a particular toy with the infant.

The Statement of Commitment (SOC) was voluntary and each participant was asked to complete and sign the SOC. Of the 33 participants in the study, 30 of them signed the SOC, noting the percentage of completion or participation of 91%.

Overall, the findings of this study did suggest the educational class was perceived to be an effective teaching method against the dangers of SBS. The results from the questionnaire validated that the parents felt the class was helpful; the participants further noted the class would be helpful for others and the participants planned to disseminate the information gained from the class with others who cared for their infant. Furthermore, the telephone follow-up indicated the participants did indeed share the information with others who cared for their infants. In addition, several participants provided suggestions and comments of additional strategies which can be used as suggestions in future education classes.

The second study (Chapter 4) was a qualitative research design. This study aimed to explore the parents' perspectives on the lived experience of infant crying. The research questions were:

1) How do the parents react to infant crying?

2) How does the parent cope with infant crying and what type of techniques or interventions do they use to help with infant crying?

3) How is excessive crying or inconsolable crying described by the parent?

4) What time of the day does the infant cry?

Through this phenomenological exploration, the participants described how they experienced the phenomenon of infant crying. The data were analyzed and several key themes were discovered. The first theme that emerged was longing for answers. The participants (parents) would often question what was wrong with the infant when the crying was persistent, excessive or inconsolable, as if to alleviate the crying or find the cause of the crying. The parents also discussed how they questioned themselves, wondering if the crying was a reflection upon their parenting skills. The second theme was heightened emotions. The parents consistently expressed multiple feelings and thoughts they experienced in response to their infant's inconsolable crying. Those feelings were frustration, anger, sadness, helplessness, stress, isolation, guilt, depression and a sense of being overwhelmed. Lastly, coping strategies emerged as a significant theme. Overall, the parents described many different strategies; however the majority of the parents mentioned that not one particular strategy consistently brought relief.

Other sub-themes were noted within the study as the parents provided information on how they described or understood excessive or inconsolable crying and the pattern of crying episodes. Many of the participants described excessive or inconsolable crying as very loud, grating and a constant and persistent cry; despite multiple attempts, nothing they did would stop the crying or it only stopped momentarily. Often these crying bouts showed no warning or sign to anticipate the upcoming crying bouts. These findings were somewhat consistent or related to other descriptions within the crying literature of describing excessive crying. Barr (2005) describes excessive crying as a crying more than expected or the crying is more relative of what is viewed as normal and tolerated by the caregiver; he also concludes the excessive crying may include fussing or fretting to inconsolable crying and progress to screaming. The parents also noted consistent crying patterns of afternoon and evening crying. This concurs with the pattern described in research studies of Barr (Hunziker & Barr, 1986; Barr 1990), Brazelton (1962), and Wessel and colleagues (1954) with crying demonstrating an afternoon or evening pattern.

In conclusion, this study was exploratory in nature examining parents' perspectives of their feelings, perceptions and thoughts regarding infant crying and living with a crying infant. The findings are significant for providing insight on how to further educate parents and caregivers on coping with infant crying.

The third study (Chapter 5) aimed to describe the behaviors, actions and emotions in which parents engaged when responding to infant crying. This was explored by participant observations in which the researcher had the opportunity to observe what the parent experienced and reveal the essence of these experiences in their lives. The four

participants were also involved in the second study (Chapter 4). The research questions were:

1) What was the parent's behavior when their infant was crying?

2) What are the types of activities in which the parent engaged in when responding to their crying infant?

3) How did the parent describe their feelings when responding to infant crying?

Observations allowed the researcher the potential opportunity to know what the parent experienced and to some extent allowed the researcher to vicariously experience the phenomenon, in response to infant crying. The data were analyzed and multiple patterns or themes emerged as the parents demonstrated how they coped and responded to infant crying. The themes included: immediate response of holding infant, routines and utilizing movement as a coping strategy.

An interesting pattern noted by the majority of the participants was the type of strategies they enlisted in coping with the crying. The strategies the parents reported or were observed performing followed the same soothing strategies described by Barr (2004). Those included six different techniques: swaddling, movement, touch, sounds, warmth, and something different, such as a distraction (Barr, 2004). The most reported type of movement to help comfort the infant was walking with their infant while gently swaying or bouncing the infant in their arms.

The emotions demonstrated and described by the parents during the participant observations proved to be beneficial and enlightening. It allowed the researcher to see the frustration, fatigue, stress, concern, helplessness, aggravation and exhaustion the

parent experienced when their child demonstrated inconsolable or excessive crying. This allowed greater insight into how the parents actually felt and managed their emotions in response to infant crying.

In summarizing the significant findings of this line of research, an area of particular interest for all three studies was the triangulation of the data. In other words, the coping strategies reported in all three studies were similar and supported each other, thereby triangulating significance of the findings. Those adaptive coping strategies reported, described or observed followed the same format as strategies suggested by Barr (2004). Triangulation was also noted by the themes emerging from studies two and three. Those themes were reinforced and thereby supported and explained the parent's lived experience of responding to infant crying.

The Relationship of the Findings to the Occupational Adaptation Frame of Reference

The occupational adaptation frame of reference (Schkade & Schultz, 1992; Schultz & Schkade, 1992) is viewed as a normal developmental process that leads to competence in occupational functioning and focuses on the internal adaptation process of humans. Occupational adaptation is a holistic approach noting the occupational environment, the person, and their interaction are all of equal importance (Schkade & Schultz, 1992). Pasek & Schkade (1996) summarized the fundamental premise of occupational adaptation as "humans are occupational beings who are faced, throughout their life span, with the need to respond to occupational challenges to promote health and well being."(p. 25).

Using occupational adaptation to examine a parent's response to infant crying, the internal state of the parent (during their response) can be viewed as moving toward a functional and meaningful resolve of coping with their crying infant. For example, Erin, a mother of two small children, and a participant in studies 2 & 3, described how motherhood is challenging, but how she has adapted and responded to the demands of the environment, and press for mastery resulting in her adaptive occupational response. Her response to the challenges of motherhood:

> I guess it has been kind of maybe a bit of a challenge because I don't want to hurt my daughter's feelings, you know, while I spend time with her. So juggling that I guess can get kind of tricky. I have learned a lot more than I thought I could...Like holding my crying baby [son] in this arm and I put my 2 year old [daughter] in this hand and take a drink or something or feed the other one at the same time. I mean I have learned to multitask, you know. I have learned to overcome the challenges.

Future research studies based upon the occupational adaptation frame of reference (OA) might consist of studying the process of relative mastery in regard to the parent's response to infant crying. Relative mastery is comprised of three areas: 1) Efficiency (using time, energy and resources), 2) Effectiveness (to what extent did the response achieve the desired goal), and 3) Satisfaction to self and others (the individual experiences satisfaction as well as the relevant society) (Schkade & McClung, 2001). According to Pasek and Schkade (1996), relative mastery is a mechanism for the individual to evaluate their occupational response, and this evaluation may lead to

learning, adaptation, and enhancement of one's occupational functioning. Therefore, the individual could reflect on their responses and coping strategies involving infant crying and in the process learn, adapt, and enhance their future strategies and coping skills in responding to inconsolable infant crying.

The results of the three studies support future research involving OA that incorporates a measurement of outcomes in terms of relative mastery with co-occupation as a focus. The study could be accomplished by incorporating an updated curriculum of the parent education class to include information on: the process of co-occupations in relation to infant crying; the utilization of movement as a coping strategy; and the measurement of the parent's efficiency, effectiveness and satisfaction of their response to infant crying. A follow-up telephone survey could then be utilized to measure the parent's relative mastery in regard to the parent education class. Having occupational therapy contribute to the design and delivery of curriculum materials for the parent education class, as described, provides a unique approach to the prevention of SBS.

Implications for Occupational Therapy

Many occupational therapists have provided interventions for infants and children who have been victims of SBS. However, few articles exist in the occupational therapy literature on our intervention with SBS and very limited information exists in establishing primary prevention programs against child abuse from an occupational therapy perspective. It is important for our profession to be involved in the development and implementation of primary prevention programs and to determine if these prevention programs are an effective means to help in the fight against SBS. This dissertation

attempted to provide an occupational therapy perspective on establishing a prevention program and to further explore the parent's feelings, thoughts and emotions in response to infant crying.

SBS is devastating and disturbing but it is also preventable. Primary prevention efforts on the dangers of shaking an infant, anger management, and adaptive coping strategies are critically important components to include in the education of SBS. What typifies SBS is the parent or caregiver demonstrates difficulty in dealing with stress and poor impulse control during their occupational role of responding to infant crying. Study 1 (Chapter 3) demonstrated an example of a prevention program addressing the occupational role of responding to infant crying and the dangers of SBS.

Historically, prevention programs within the profession of occupational therapy have addressed tertiary prevention at mainly individual levels. The role for occupational therapy in primary prevention is supported in several professional documents. Those include: the *Guide to Occupational Therapy Practice* (Moyers, 1999) and *Occupational Therapy in the Promotion of Health and Prevention* (Brownson & Scaffa, 2001). In addition, the *Occupational Therapy Practice Framework: Domain and Process* supports health promotion and prevention (AOTA, 2002).

The national document, *Healthy People 2010,* provides a comprehensive national health promotion and disease prevention plan and identifies 28 focus areas. Injury and violence prevention is listed as a focus area and *Healthy People 2010* encourages and promotes interdisciplinary efforts. In addition to a hospital based prevention program, another viable prevention venue for occupational therapists is through community based

intervention. In providing community based intervention and networking with community agencies, governmental agencies, and federal, state and local prevention agencies, therapists can expand their role beyond traditional approaches to encompass primary prevention strategies. As occupational therapists, we can be involved in the education of infant crying and the dangers of SBS though our work with infants, parents and the community. By networking and resourcing with other professionals in the campaign against SBS, the occupational therapist works in the role of a consultant, collaborator and contributor (Scaffa, Desmond & Brownson, 2001). Occupational therapy brings valuable knowledge, insight and experience on participation and occupation to support the interdisciplinary efforts on the prevention of SBS.

Our valuable knowledge, insight and experience of participation and occupation support another role for occupational therapists. Because of our skills in studying occupations, we are in a position to support and engage in future research studies to further explore and understand the occupational role of parenting, more specifically the parent's response to infant crying. Occupational therapy's description of co-occupations (Zemke & Clark, 1996 & Olson, 2004), specifically infant crying, supports our engagement in listening and exploring the parent's perspective as well as examining the infant's role in crying. Llewellyn (1994) discusses the notion and importance for our profession to explore the meaning, values and intentionality of parenting. The parent is viewed as the true expert as the caregiver for their infant. More research into pursuing the parent's perspective of infant crying could provide important findings to strengthen and expand primary prevention programs.

Future Research

As previously mentioned, future research regarding consistent tracking measures of the incidence of SBS and consistent and coordinated prevention programs encompassing an entire city, county or region will help to provide and determine the incidence of a decrease in SBS, which is the ultimate goal of a prevention program. This type of a prevention program would entail networking, consulting, cooperating, and collaborating with multiple hospital personnel, community health workers, as well as city, county and regional members of the legal system and health department.

Understanding and respecting infant crying is a critical component for all professionals who work with infants and parents to help convey and reassure the parent that crying is a normal part of infant development and behavior. However, it is equally important to understand, listen and validate the parent's feelings and emotions that they are experiencing in coping with infant crying. This may be done by providing a support system or network of professionals, parents and other caregivers for parents to discuss their feelings and offer encouragement and reassurance. It is essential that professionals be attuned to parents' responses to infant crying since crying is the main precipitating factor in cases of Shaken Baby Syndrome (Nakagawa & Conway, 2004). Education and primary prevention efforts that include understanding infant crying, the dangers of shaking an infant, and adaptive coping strategies for parents are paramount.

Research Limitations

The first study, conducted within a hospital based NICU, did find that the parents viewed the class to be an effective method of addressing infant crying and conveying the

dangers of SBS. However, further studies are needed to encompass a larger aspect of newborn education with caregivers in perhaps all of the hospitals within the city or county. Also, while the education class did support prevention of SBS, it was not able to track the incidence of a decrease in the reports of SBS. This type of tracking would be essential to determine the ultimate effectiveness of a prevention program.

Another limitation of this research is the small sample size, in particular, studies two and three (chapters 4 & 5). Also the two qualitative studies were conducted with only one ethnic or racial group represented (Caucasian). In regards to family dynamics, all of the participants were married parents; none were single parents and all had to some extent a support system of their spouse and, in several cases, other family members to call or provide assistance in care giving with their infant.

Research Process

The research process overall was engaging, encouraging and enlightening but not without difficulty or fault. I found it challenging to juggle data collection with two studies occurring almost simultaneously. In study one, the telephone survey did show some concerns and disappointments, as several of the telephone numbers listed by the participants were numbers no longer in service or several of the participants were unable to be reached, despite multiple attempts in telephoning many of them. However, the majority of those contacted did prove to be descriptive and informative in regard to their responses. The education class conducted within the NICU was often times provided at the end of a long working day. However, each time the class met, I came away refreshed, encouraged and reassured that the purpose and intent of the class was beneficial and

helpful for the parents and caregivers, which provided the incentive to stay true to my overall goal and passion, the prevention of SBS.

I also found that it was helpful to write my field notes immediately following the interviews and observations, as the longer I waited to write in the field journal, the more likely I was to not fully capture my thoughts and reflections. The participant observations were especially challenging. I used an observation grid to assist in gathering the information. However, if I were to engage in future studies utilizing participant observations, I would enlist using a video camera or tape recorder to help capture all of the nuances, activities and conversations that transpired during the observations in addition to the observation grid.

One final reflection, I was pleasantly surprised and pleased to engage in very personal and often times emotional conversations with many of these parents. I am truly grateful to their openness, honesty and sincerity as it further solidified my desire to learn and gain knowledge of their true lived experiences and supported and validated why it is important to "listen to their voices".

In conclusion, the results of Shaken Baby Syndrome are irreversible; however the opportunities for prevention are plentiful. These prevention opportunities, simply stated, could perhaps make the difference in saving the life of an innocent child. I would like to close with a quote regarding opportunities that was presented to a group of occupational therapists over 80 years ago, yet still stands true today:

> It takes rare gifts and talents and rare personalities to be real pathfinders in this work. There are no royal roads; it is all

a problem of being true to one's nature and opportunities and

of teaching others to do the same with themselves (Meyer, 1922, p. 7).

REFERENCES

Alexander, R.C., Levitt, C.J., & Smith, W.L. (2001). Abusive head trauma in *Child abuse: Medical diagnosis and management* by Reece, R.M. and Ludwig, S., 2nd edition. Lipponcott Williams and Wilkins, Philadelphia, Pennsylvania

Alexander, R.C. & Smith, W.L. (1998). Shaken Baby Syndrome. *Infants and Young Children.* 10(3), 1-9.

American Academy of Pediatrics: Committee on Child Abuse and Neglect. (2001). Shaken Baby Syndrome: Rotational Cranial Injuries-Technical Report. *Pediatrics, 108*, No. 1, 206-210.

American Occupational Therapy Association (2002). Occupational therapy practice framework: Domain and process. *American Journal of Occupational Therapy, 56*, 609-639.

American Association of Neurological Surgeons. (2000). *Shaken baby syndrome-A potentially deadly concern.* Retrieved May 2, 2007, from http://www.medem.com/search/article_display.cfm?path=\\TANQUERAY\M_ContentItem&mstr=/M_ContentItem/ZZZ9G8DUE8C.html&soc=AANS&srch-typ=NAV_SERCH

Barr, R.G. (1990). The normal crying curve: What do we really know? *Developmental Medicine and Child Neurology,* 32, 356-362.

Barr, R.G., Konner, M., Bakeman, R., & Adamson, L. (1991). Crying in Kung infants: A test of the cultural specificity hypothesis. *Developmental Medicine and Child Neurology,* 33, 601-610.

Barr, R.G., Chen, S., Hopkins, B., & Westra, T. (1996). Crying patterns in preterm infants. *Developmental Medicine and Child Neurology, 38,* 345-355.

Barr, R.G., Hopkins, B., & Green, J.A. (Eds.) (2000). *Crying as a Sign, a Symptom and a Signal. Clinical, emotional and developmental aspects of infant and toddler crying.* London: Mac Keith Press.

Barr, R.G. (2004). Crying. *The Parent Review,* Vol. 2, no. 2, 1-4

Barr, R. G., Paterson, J.A., MacMartin, L.M., Lehtonen, L. & Young, S.N. (2005). Prolonged and unsoothable crying bouts in infants with and without colic. *Journal of Developmental & Behavioral Pediatrics,* February 2005, vol. 26.

Brazelton, T.B. (1962). Crying in infancy. *Pediatrics, 29,* 579-588.

Brownson, C.A. & Scaffa, M.E. (2001). Occupational therapy in the promotion of health and the prevention of disease and disability. *American Journal of Occupational Therapy, 55,* 656-660.

British Lullaby. *Hush, Little Baby.* Author unknown. Retrieved August 5, 2007 from: http://en.wikipedia.org/wiki/hush%2C_Little_Baby

Butler, G.L. (1995). Shaken baby syndrome. *Journal of Psychosocial Nursing, 33,* 47-50.

Caffey, J. (1946). Multiple fractures in the long bones of infants suffering from chronic subdural hematoma. *American Journal of Roentgenology,* 56, 163-173.

Caffey. J. (1972). On the theory and practice of shaking infants. *American Journal of the Diseases of Children,* 124, 161-169.

Caffey, J. (1974). The whiplash-shaken infant syndrome: Manual shaking by the extremities with whiplash-induced intracranial and intraocular bleedings, linked with residual permanent brain damage and mental retardation. *Pediatrics,* 54, 396-402.

Castiglia, P.T. (2001). Shaken baby syndrome. *Journal of Pediatric Health Care, 15,* 78-80.

Conway, E.E. (1998). Nonaccidental head injuries in infants: "The shaken baby syndrome revisited." *Pediatric Annals,* 27, 677-690.

Crowe, H.P. & Zeskind, P.S. (1992). Psycho-physiological and perceptual responses to infant cries varying in pitch: comparison of adults with low and high scores on the Child Abuse Potential Inventory. *Child Abuse and Neglect,* 16, 19-29.

Dias, M.S., Smith, K., deGuehery, D., Mazur, P., Li, V., & Shaffer, M.L. (2005). Preventing abusive head trauma among infants and young children: A hospital-based, education program. *Pediatrics, 115,* 470-477. doi: 10.1542/peds.2004-1896

Duhaime, A., Christian, C., Rorke, L., & Zummerman, R. (1998). Nonaccidental head injury in infants-"The Shaken-Baby Syndrome." *The New England Journal of Medicine,* 338 (25), 1822-1829.

Fielding, N. & Fielding, J. (1986). *Linking data.* Beverly Hills, CA: Sage

Frodi, A. (1985). When empathy fails: Aversive infant crying and child abuse. In In B.M. Lester & C.F. Z. Boukydis (Eds.), *Infant Crying: Theoretical and Research Perspectives* (pp.263-278). New York: Plenum Press.

Guthkelch, A.N. (1971). Infantile subdural hematoma and its relationship to whiplash injuries. *British Medical Journal,* 2, 430-431.

Gutierrez, F.L., Clements, P.T., & Averill, J. (2004). Shaken baby syndrome: Assessment, intervention, and prevention. *Journal of Psychosocial Nursing and Mental Health Services, 42* (12), 23-29.

Homor, G. (2005). Physical abuse: Recognition and reporting. *Journal of Pediatric Health Care, 19* (1), 4-11. doi: 10.1016/j.pedhc.2004.06.009

Hunziker, U.A. & Barr, R.G. (1986). Increased carrying reduces infant crying: a randomized controlled trial. *Pediatrics. 77*, 641-648.

Jorgensen, D.L. (1989). *Participant Observation: A methodology for human studies.* London, England: Sage Publications.

Lazoritz, S., Baldwin, S. & Kini, N. (1997). The whiplash shaken infant syndrome: Has Caffey's syndrome changed or have we changed his syndrome? *Child Abuse and Neglect, 21*, 1009-1014.

Lester, B. (1985). There's more to crying than meets the ear. In B.M. Lester & C.F. Z. Boukydis (Eds.), *Infant Crying: Theoretical and Research Perspectives* (pp. 1-27). New York: Plenum Press.

Llewellyn, G. (1994). Parenting: A neglected human occupation. Parent's voices not yet heard. *Australian Occupational Therapy Journal, 41*, 173-176.

Long, T. & Johnson, M. (2001). Living and coping with excessive infantile crying. *Journal of Advanced Nursing, 34* (2), 155-162.

Long, T. (2006). Unpublished questionnaire. Obtained on February 23, 2006 via email.

Ludington-Hoe, S.M., Cong, X., & Hashemi, F. (2002). Infant Crying: Nature, Physiologic Consequences, and Select Interventions. *Neonatal Network,* Vol. 21, No. 2, 29-36.

MacDonald, S., & Helfrich, C.A. (2001). Shaken baby syndrome: Assessment and treatment in occupational therapy. *Occupational therapy in Mental Health, 16* (3/4), 111-125.

Maxwell, J. (2005). *A qualitative research design: An interactive approach.* Second edition. Thousand Oaks, CA: Sage Publications.

Meyer, A. (1922). The Philosophy of Occupation Therapy. *Archives of Occupational Therapy,* Vol. 1, no. 1, 1-10.

Moyers, P. (1999). The guide to occupational therapy practice. *American Journal of Occupational Therapy, 52*, 247-322.

Murry T. & Murry J. (1980). *Infant Communication: Cry and Early Speech.* Houston, Texas: College-Hill Press.

Nakagawa, T.A., & Conway, E.E. (2004). Shaken baby syndrome: Recognizing and responding to a lethal danger. *Contemporary Pediatrics, 21* (3), 37-57.

National Center on Shaken Baby Syndrome. (2003). *Understanding Shaken Baby/ Shaken Impact Syndrome.* (Brochure). Ogden, Utah: Author.

National Center on Shaken Baby Syndrome. *It takes only a few seconds to charge lives forever.* Retrieved February 8, 2005, from: www.dontshake.com

Patton, M.Q. (2002). *Qualitative Research and Evaluation Methods* (3rd edition). London, England: Sage Publications.

Peinkofer, J.R. (2002). *Silenced angels: The medical, legal and social aspects of shaken baby syndrome.* Westport, CT: Auburn House.

Poskey, G.A. (2005). Shaken baby syndrome: Prevention from an occupational therapy perspective. *OT Practice, 10* (22), 17-21.

Prevent Child Abuse America. (2006). *Child abuse prevention month.* Chicago: Author.

Olson, J.A. (2004). Mothering Co-occupations in Caring for Infants and Young Children. In S.A. Esdaile & J.A. Olson's *Mothering Occupations: Challenge, Agency, and Participation.* (pp. 28-51). Philadelphia: F.A. Davis.

Pasek, P.B. & Schkade, J.K. (1996). Effects of s skiing experience on Adolescents with limb deficiencies: An occupational adaptation perspective. *American Journal of Occupational Therapy,* 50, 24-31.

Scaffa, M.E., Desmond, S. & Brownson, C.A. (2001). Public health, community health, and occupational therapy. In M.E. Scaffa's *Occupational Therapy in Community- Based Practice Settings.* (35-50). Philadelphia: F.A. Davis.

Schkade, J. & Schultz, S. (1992). Occupational adaptation. Toward a holistic approach for contemporary practice, Part 1. *American Journal of Occupational Therapy, 46,* 829-837.

Schultz, S. & Schkade, J. (1992). Occupational adaptation: Toward a holistic approach for contemporary practice, Part 2. *American Journal of Occupational Therapy, 46*, 917-925.

Schkade, J. & McClung, M. (2001). *Occupational Adaptation in Practice: Concepts and Cases.* Thorofare, NJ: Slack.

Shaken Baby Alliance. (2004). *When Babies Cry.* [DVD]. Fort Worth, TX: Author.

Showers, J. (1992). "Don't shake the baby": The effectiveness of a prevention program. *Child Abuse & Neglect, 16* (1), 11-18.

Showers, J. (2001). Preventing Shaken Baby Syndrome. In S.L. Lazoritz & V.J. Palusci (Eds.), *The Shaken Baby Syndrome: A Multidisciplinary Approach,* (349-365). New York: The Haworth Maltreatment & Trauma Press.

Simons, B., Downs, E.F., Hurster, M.M., & Archer, M. (1996). An epidemiologic study of medically reported cases of child abuse. *New York State Medical Journal,* 66, 2783-2788.

Small, M.E. (1998). *Our Babies, Ourselves: How Biology and Culture Shape the Way We Parent.* New York: Anchor Books

Spencer, J.C. (2003). Evaluation of performance contexts. In E.B. Crepeau, E.S. Cohn, & B.B. Schell (Eds.). *Willard & Spackman's Occupational Therapy.* (427-448). Philadelphia: Lippincott Williams & Wilkins.

Tennyson, A.L. *In Memoriam A.H.H.* Retrieved July 19, 2007 from: http://www.online-literature.com/authorsearch.php

U.S. Department of Health, Education and Welfare. (2000). *Healthy people 2010.* Washington, DC: U.S. Department of Health and Human Services.

Wessel, M.A., Cobb, J.C., Jackson, E.B., Harris, G.S., & Detwiler, A.C. (1954) Paroxysmal fussing in infancy, sometimes called "colic". *Pediatrics,* 14, 421-434.

Zemke, R. & Clarke, F. (Eds.). (1996). *Occupational science the evolving discipline.* Philadelphia: F.A. Davis Co.

APPENDIX A

IRB Approvals

BAYLOR
Research Institute
Affiliated with Baylor Health Care System

3310 Live Oak
Suite 501
Dallas, Texas 75204
(214) 820-2687
(214) 820-4952 Fax
www.BaylorHealth.com

IRB APPROVAL

October 6, 2006

Gail A. Poskey, MOT, OTR
Physical Medicine and Rehabilitation
Baylor University Medical Center
3500 Gaston Avenue
Dallas, TX 75246

Re: Shaken Baby Syndrome: Evaluating the Effectiveness of a Parent Education Class
Project#: 006-197 Protocol#: N/A Protocol Dt:
Sponsor: Baylor Department

The following items received expedited review:

- Research Protocol (Not Dated)
- Consent Form/Survey (10/05/2006)
- List of Resources (10/05/2006)
- Signature of Commitment (10/05/2006)
- Telephone Follow-Up Script (10/05/2006)
- Education Report (09/27/2006)
- IRB Form 1 - Application and Project Summary (09/25/2006)
- IRB Form 18 - Review of Scientific and Scholarly V (09/25/2006)

Expedited Approval was granted 10/09/2006 for a period not to exceed 12 months and will expire on 10/08/2007. Your Continuing Review is scheduled for 09/20/2007. This Expedited review will be reported to the fully convened Institutional Review Board ~ White on 10/19/2006.

On behalf of the Institutional Review Board, I have reviewed the above referenced research project in accordance with 45 CFR 46 & 164 and 21 CFR 50 & 56. This review was conducted in accordance with the expedited review process as outlined in 45 CFR 46.110(b). Based on the information presented, I have determined that the study meets the criteria specified below. NOTE: The list of categories is from the November 9, 1998 Federal Register.

45 CFR 46.110(b)(1)(7):
(1) some or all of the research appearing on the category list and found by the reviewer(s) to involve no more than minimal risk:

(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior), or research employing survey, interview, oral history, focus groups, program evaluation, human factors evaluation, or quality assurance methodologies. (NOTE: some research in this category may be exempt from the HHS regulations for the protection of human subjects 45 CFR 46.101(b)(2) and (b)(3). This listing refers only to research that is not exempt.

Based on this review, the above referenced items are approved for implementation.

The Board reminds you that Baylor Policy requires that that unless waived, fully documented informed consent must be obtained in accordance with 45 CFR 46.116 and 21 CFR50.20 from all human subjects involved in this research study. Informed consent must be obtained by the principal investigator or other key personnel as listed in this submission. Documentation of informed consent must be kept on file for a period of three years past completion or discontinuation of the study and will no doubt be subject to inspection in the future.

In addition, 45 CFR 164 requires that, unless waived by the IRB, authorization must be obtained for use and disclosure of Protected Health Information. If this project is currently open to new enrollment, the approved version of the consent form(s) is listed above. The document(s) reviewed in this submission has been determined to satisfy the requirements as outlined in 45 CFR 164.508.

DHHS and FDA regulations require you to submit periodic and terminal progress reports to Baylor's Institutional Review Board and to receive at least annual approval of your activity from this Committee.

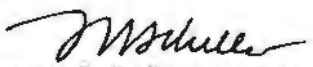
You are also required to report to this Committee immediately any death, unanticipated problems invoving risks to subjects or others, or serious adverse incidents resulting from your study. These events must be reported in accordance with current BRI Policies 830 and 838.

Federal regulations and institutional policies require that the IRB review any and all changes in your research activity. This includes amendments, revisions, administrative changes, advertisements, or ANY other change in the information as presented at initial review. In other words, should your project change, another review by the Board is required. Failure to comply with any of the above requirements, federal regulations, or institutional policy may result in severe sanctions being placed on the Medical Center and on you as the Principal Investigator. These sanctions could result in your research being permanently terminated for non-compliance.

Receipt of approval does not convey institutional authority to gain additional patient information. It is your responsibility as Principal Investigator to abide by institutional and/or departmental policies regarding confidentiality, access, and release of patient data.

Please be advised: there may be additional administrative requirements from Baylor Research Institute that must be met before the study may begin enrolling subjects.

Sincerely,



Lawrence R. Schiller, MD, Chair
Institutional Review Board ~ White

TEXAS WOMAN'S UNIVERSITY
DENTON DALLAS HOUSTON
INSTITUTIONAL REVIEW BOARD
6700 Fannin, Houston, Texas 77030 713/794-2074

MEMORANDUM

TO: Gayle Hersch
Gail A. Poskey Student ID #0045038

FROM: IRB

DATE: December 6, 2006

SUBJECT: IRB Exempt Application

TITLE: Shaken baby syndrome: Evaluating the effectiveness of a parent education class

This application is approved. This approval lasts for 1 year. The study may not continue after the approval period without additional IRB review and approval for continuation. It is your responsibility to assure that this study is not conducted beyond the expiration date.

Any changes in the study must receive review and approval prior to implementation unless the change is necessary for the safety of subjects. In addition, you must inform the IRB of adverse events encountered during the study or of any new and significant information that may impact a research participant's safety or willingness to continue in your study.

Gretchen Gemeinhardt, Ph.D.
Chairperson

TEXAS WOMAN'S UNIVERSITY
DENTON DALLAS HOUSTON
Institutional Review Board
6700 Fannin, Houston, Texas 77030 713/794-2074

MEMORANDUM

TO: Gayle Hersch
Gail A. Poskey Student ID# 0045038

FROM: IRB

DATE: November 6, 2006

SUBJECT: IRB Application

Proposal Title Exploration of parent perspectives and adaptation to Shaken Baby Syndrome: An occupational therapy approach

Your application to the IRB has been reviewed and **approved.**

This approval lasts for 1 year. The study may not continue after the approval period without additional IRB review and approval for continuation. It is your responsibility to assure that this study is not conducted beyond the expiration date.

Any changes in the study or informed consent procedure must receive review and approval prior to implementation unless the change is necessary for the safety of subjects. In addition, you must inform the IRB of adverse events encountered during the study or of any new and significant information that may impact a research participant's safety or willingness to continue in your study.

REMEMBER TO PROVIDE COPIES OF THE SIGNED INFORMED CONSENT TO THE OFFICE OF RESEARCH, HHS 1011 WHEN THE STUDY HAS BEEN COMPLETED. INCLUDE A LETTER PROVIDING THE NAME(S) OF THE RESEARCHER(S), THE FACULTY ADVISOR, AND THE TITLE OF THE STUDY. GRADUATION MAY BE BLOCKED UNLESS CONSENTS ARE RETURNED.

Gretchen Gemeinhardt, Ph.D.
Chairperson

IRB APPROVAL FORM

Name of Investigator(s)	Gail A. Poskey
TWU ID# (s)	0045038
Name of Research Advisor(s)	Gayle Hersch, PhD, OTR
Address:	Institute of Health Sciences-Houston Center
	6700 Fannin Street
	Houston, TX 77030
Type of Review:	Full ☐ Expedited ☒

Dear:

Your study entitled:
(The applicant must complete the top portion of this form)

has been reviewed by the **Institutional Review Board** - Houston Center and it appears to meet our requirements in regard to protection of the individual's rights.

Please be reminded that both the University and the Department of Health and Human Services regulations typically require that signatures indicating informed consent be obtained from all human subjects in your study. These are to be filed with the **Institutional Review Board** Chairman. Any exception to this requirement is noted below. Furthermore, according to HHS regulations, **another review by the IRB is required if your project changes or if it extends beyond one year from this date of approval.**

Any special provisions pertaining to your study are noted below:

_____The filing of signatures of subjects with the Institutional Review Board is not required.

_____Other: see attached sheet.

_____No special provisions apply.

Sincerely,

Gretchen Gemeinhardt, PhD
Chair, IRB - Houston Center

November 6 2006
Date

APPENDIX B

Data Collection Forms and Resource Guide for Study I

IRB 006-197 October 5, 2006

Neonatal Intensive Care Unit of Baylor University Medical Center
Dallas, Texas

Would you please help us track the effectiveness of this program?

You are being asked to take part in a research study to help us track the effectiveness of this program. You are being asked to voluntarily complete this questionnaire to help track the effectiveness of this education class on: Infant crying and the dangers of Shaken Baby Syndrome. You are alsobeing asked to voluntarily provide a telephone number where the study coordinator may call you in about 2 to 3 months to ask you a few questions and to follow-up on your recall of the information you received in the class today. You may refuse to take part in this study, and the medical care for your baby will not be affected in any way. The information you give is all confidential. The overall results of this program will he collectively used to measure how effective the class and matehals are and may be presented at conferences and written in journals, but no identifying information about you or any other person who is in the study will be given. You are free to withdraw from this project at any time. By signing this form you are saying that you have read this information, your questions have been answered and you consent to take part in this study. If you have questions you may call Gail Poskey, OTR, study coordinator at (214) 820-1323. If you have questions about your rights as a research subject you may call Dr. Lawrence R. Schiller, Baylor IRB Chair at (214) 820-2687.

I agree to take part in this project:

(Please only sign for yourself, your spouse or partner will fill-out a separate form)

Mother's Name_____

Signature_____

Father's Name_____

Signature_____

Baby's Date of Birth ___/___/___ Was your infant born prematurely ___Yes ___No, If yes, how many weeks? _____

Baylor Research Institute
IRB Approval
This project is approved from
10-5-2006 to 10-5-2007

What is your age? _____

What is your highest education?

Some high school	☐
High school graduate	☐
Some college	☐
College graduate	☐
Post-college degree (Masters, PhD)	☐

Is this the first time you have heard that shaking an infant is dangerous? ☐ **Yes** ☐ **No**

Did you find the video helpful? ☐ **Yes** ☐ **No**

Was this the first time you have heard of ways to cope with a crying infant? ☐ **Yes** ☐ **No**

Was the information discussed today helpful? ☐ **Yes** ☐ **No**

Do you think it would be helpful for other parents to attend this class? ☐ **Yes** ☐ **No**

Will you share the information you received today with others who may care for your infant?

☐ **Yes** ☐ **No**

May we call you in 2 to 3 months to ask about your recollections of this information?

☐ **Yes** ☐ **No**

If you answered yes, please provide a telephone number where we may reach you :

(___) ___-_____

Any comments about this program?

_____

_____

_____

(Dias, et al, 2005).

Thank you for your time in participating in this program!

Baylor Research Institute
IRB Approval
This project is approved from
10-5-2006 to 10-5-2007

IRB 006-197 October 5, 2006

BAYLOR
University Medical Center
at Dallas

3500 Gaston Avenue
Dallas, Texas 75246
(214) 820-0111

Neonatal Intensive Care Unit of Baylor University Medical Center
Dallas, Texas

Statement of Commitment

I_____(Your Name) have received the information about infant crying and Shaken Baby Syndrome. I have been asked to voluntarily sign a statement of commitment to acknowledge I have received, read and understand this information and understand that shaking a baby is dangerous and may even cause death. (Dias et al, 2005; Showers, 2001).

Signature: _____. Date: _____

Telephone Follow-up:

Did you find the strategies/interventions discussed in class to be helpful?

☐ Yes ☐ No

Which strategies/interventions have you used? _____

_____

Have you shared information from the class with others who care for your baby?

☐ Yes ☐ No. **If yes, who have you shared this with?**

_____

What other additional strategies/interventions have you used in responding to your crying infant? _____

_____

Any other comments you may have?

_____

_____

Appendix B

List of Resources

Childhelp USA: 1 (800) 422-4453 or 1 (800) 4-A-CHILD

Contact Counseling: (972) 233-2233 or 1 (800) 273-8255

Dallas Association for Parent Education WarmLine: (972) 699-7742

Dallas Metro Care Crisis Line: 1 (866) 260-8000

National PPD Moms: 1 800-PPD-MOMS (1-800-773-6667)

Texas: 211 - A 24 hour referral and hotline in the state of Texas

APPENDIX C

Data Collection Forms for Study II & Study III

Questionnaire

Today's Date: _____ **What is your age? _____**

Please tell me about your baby...

1. **What is your baby's name?** _____

2. **How old is your baby?** **Weeks_____ or Months_____**

3. **Was your baby born early, term or late?** _____
   If early how many weeks?_____
   If late how many weeks?_____

4. **What is the sex of your baby?** ☐ **Male** ☐ **Female**

5. **Is this your first baby?** ☐ **Yes** ☐ **No**

6. **If you answered no to the question 5, what baby is this?** ☐ **Second baby,** ☐ **Third baby** ☐ **Fourth baby,** ☐ **Other____**

7. **Where was your baby born?** ☐ **Hospital** ☐ **Home** ☐ **Other**

8. **Did your baby have any serious health problems at birth or soon after?** **(Please give brief details**
   _____
   _____
   _____

9. At what age of your baby did you notice your baby begin to cry more?

Weeks_____ or Months_____

10. Do you view your baby's crying as normal?

☐ Yes ☐ No If no briefly state why? _____

_____

11. Do you think your baby suffers from colic or excessive crying?

☐ Yes ☐ No

12. Have you previously dealt with a baby who cried excessively?

☐ Yes ☐ No

Please tell me about the rest of your family...

1. What is your relationship with the baby?

I am the baby's _____

2. How many people share your home? (Please include yourself and the baby)

Adults: _____

Children from 3 – 18 years: _____

Children younger than 3: _____

3. How much space do you have in your home?

☐ 1 bedroom apartment / house

☐ 2 bedroom apartment / house

☐ 3 bedroom apartment / house

☐ 4 bedroom apartment / house

Other (please specify) _____

4. Who helps provide care for your baby?

- ☐ **Your spouse**
- ☐ **Relatives**
- ☐ **Friend**
- ☐ **Paid help**
- ☐ **Other**
- ☐ **No help**

5. How long are you usually alone at home with your baby without another adult on a daily basis?

Number of hours: _____

6. Do you work outside of the home? ☐ **Yes** ☐ **No**

7. Do you have leisure time away from your baby? ☐ **Yes** ☐ **No**

Thank you for your responses and for agreeing to participate in this interview.

(Long, 2006).

Interview Questions

Parenthood

1. Please tell me about your baby?

   Please describe their personality?

2. How has motherhood or fatherhood been for you with this baby?

   How is that?

   Any surprises?

   How does your actual experience differ from your expectations?

   How would you say you are enjoying motherhood or fatherhood?

Crying Episodes

1. Please tell me about the first time your infant really cried? How did you feel?
2. Tell me about how often does your baby cry?
3. At what age did you notice your baby begin to cry more?

   What time of the day does your baby cry more?

4. When your baby was 6 to 8 weeks old did you notice any difference in their crying or the amount of crying?
5. What types of cries does your baby have?

Response to Crying

1. How do you respond to your infant crying?

   What is the process of how you respond to their crying, would you take me through your routine?

2. When the crying will not stop, what strategies or activities do you then use?

   Will you please describe those activities or strategies?

3. How often does it happen that your baby will not stop crying?

Feelings and thoughts about crying

1. Describe your feelings and thoughts when your baby has a long bout of crying or inconsolable crying?

   Describe your actions?

2. What do you do for yourself when your baby will not stop crying or has those long bouts of crying?

Coping with crying

1. Would you say you have learned to cope or adapt to your infant's crying?

   Please tell me how?

2. What sorts of words describe your family's reaction to your baby's crying? Say your spouse or your other children's reaction to your baby's crying?

3. How would you describe your baby's long bouts of crying? As inconsolable crying or as colic?

   Would you describe what is inconsolable crying or colic?

   Do your feel this crying is normal for your baby? How so?

SBS

1. Have you heard about Shaken Baby Syndrome, could you describe what SBS is?
2. What feelings do you think those parents or caregivers have that causes them to shake their baby?

Closing questions

1. What is your favorite activity you like to do with your baby?
2. Anything else you would like to share about your infant or about being a father or mother in regard to infant crying?

Participant Observation Chart

Code: _____ Date: _____
Time observed: _____

Child care activities: (i.e. Feeding, diaper change) **Observations:** **Parents Behavior:**
Play activities with child: (i.e. using toys, songs, facial expressions-peek-a-boo) **Observations:** **Parents Behavior:**

Strategies and Coping Activities in response to infant crying: (i.e. holding infant, rocking infant, walking with infant, swaddling infant) **Observations:**

APPENDIX D

Consent Forms

TWU
TEXAS WOMAN'S UNIVERSITY
DENTON DALLAS HOUSTON

School of Occupational Therapy
6700 Fannin Street, Houston, TX 77030-2343
713-794-2128 Fax 713-794-2122

TEXAS WOMAN'S UNIVERSITY
CONSENT TO PARTICIPATE IN RESEARCH

Title: Exploration of parent perspectives and adaptation to Shaken Baby Syndrome: An occupational therapy approach

Investigator: Gail A. Poskey, MOT, OTR.....(214)450-7296
Advisor: Gayle Hersch, PhD, OTR.....(713)794-2153

Explanation and Purpose of the Research

You are being asked to participate in a research study for Ms. Poskey's dissertation at Texas Woman's University. The purpose of this research is to explore how parents deal with infant crying. In particular this study will examine what feelings and actions are provoked when an infant cries.

Research Procedures

For this study, you will be asked to complete a questionnaire and the investigator will conduct face-to-face interviews with observations of parents with infants. The interview will be done in the privacy of your own home. You will be audiotaped during the interview and notes will be taken during the observations. The purpose of audiotaping is to provide a transcription of the information discussed in the interview and to assure the accuracy of the reporting of that information. Your total commitment time in the study is estimated to be from 1 hour 15 minutes to 2 hours 15 minutes for the interview. Total time for both the interview and observation would be a minimum of 3 hours 15 minutes and would not exceed 6 hours 15 minutes.

Potential Risks

Potential risks related to your participation in the study include loss of time, discomfort with sensitive topics or emotional distress during your interview. To avoid fatigue, you may take a break (or breaks) during the interview or observations as needed. If you experience physical or emotional discomfort regarding the interview questions, you may stop answering any of the questions at any time. If you feel as though you need to discuss the physical or emotional discomfort with a professional, the investigator will provide to you at the beginning of the interview process with a referral list of names and phone numbers that you may use.

Another possible risk to you as a result of your participation in this study is loss of confidential information. Confidentiality will be protected to the extent that is allowed by law. The interview will take place in the privacy of your home. A code name, rather than your real name, will be used on the audiotape and transcription. Only the investigator and the transcriber will have access to the tapes. The tapes, hard copies of the transcriptions, the observation sheets, and the computer disks CD's containing the transcription text files will be stored in a locked filing cabinet in the investigator's office. The tapes and CD's will be erased and the hard copies of the transcriptions and the observations sheets will be shredded within 5 years. It is anticipated that the results of this study will be published in the investigator's dissertation as well as in other research publications. However, no names or other identifying information will be included in any publication.

Participant's initials

Approved by the
Texas Woman's University
Institutional Review Board
Date: 11/6/06

Exploration of parent perspectives and adaptation to Shaken Baby Syndrome:
An occupational therapy approach

The researcher will try to prevent any problem that could happen because of this research. You should let the researchers know at once if there is a problem and they will help you. However, TWU does not provide medical services or financial assistance for injuries that might happen because you are taking part in this research.

Participation and Benefits

Your involvement in this research study is completely voluntary, and you may discontinue your participation in the study at any time without penalty. There are no direct benefits from this study; an indirect benefit of the study is the contribution to the knowledge in the field of occupational therapy. At the completion of the study, a summary of the results will be mailed to you if you request to receive the results.

Questions Regarding the Study

If you have any questions about the research study you may ask the researchers; their phone numbers are at the top of this form. If you have questions about your rights as a participant in this research or the way this study has been conducted, you may contact the Texas Woman's University Office of Research at (713) 794-2840 or via email at IRB@twu.edu. You will be given a copy of this signed and dated consent form to keep for your records.

_____ _____

Signature of Participant Date

The above consent form was read, discussed, and signed in my presence. In my opinion, the person signing said consent form did so freely and with full knowledge of its contents.

_____ _____

Signature of Investigator Date

* If you would like to receive a summary of the results of this study, please provide an address to which this summary should be sent:

_____

_____

_____

Approved by the
Texas Woman's University
Institutional Review Board
Date: 11/6/06

TWU
TEXAS WOMAN'S UNIVERSITY
DENTON DALLAS HOUSTON

School of Occupational Therapy
6700 Fannin Street, Houston, TX 77030-2343
713-794-2128 Fax 713-794-2122

CONSENT TO RECORD

Texas Woman's University

"Exploration of parent perspectives and adaptation to Shaken Baby Syndrome: An occupational therapy approach"

The undersigned consents to the recording of his/her voice by Gail A. Peskey, acting under the authority of the Texas Woman's University, for the purposes of the research project entitled "Exploration of parent perspectives and adaptation to Shaken Baby Syndrome: An occupational therapy approach." The undersigned understands that the material recorded for this research may be made available for educational and/or research purposes and consents to such use.

_____ _____
Participant **Date**

The above form was read, discussed, and signed. The person signing this consent form did so freely and with full knowledge and understanding of its contents.

_____ _____
Representative of the Texas Woman's University **Date**

Approved by the Texas Woman's University Institutional Review Board
Date: 11/6/06

APPENDIX E

Publication Correspondence

July 19, 2007

Anne E. Dickerson, PhD, OTR/L, FAOTA
Editor, *Occupational Therapy in Health Care*
Professor and Chair, Occupational Therapy Department
Health Sciences Building, 3305E
East Carolina University
Greenville, NC 27858

Dear Dr. Dickerson,

Enclosed please find one original and three copies of my original manuscript: "Shaken Baby Syndrome: A program evaluation of a parent education class", for submission to *Occupational Therapy in Health Care*. I have also enclosed a signed manuscript submission and copyright transfer form, a 9" X 12" self-addressed envelope with postage and a regular, stamped and self addressed envelope as requested.

This manuscript is not currently, nor has it been submitted to any other journal for publication. Thank you very much for considering my work.

Sincerely,

Gail A. Poskey, MOT, OTR
Senior Occupational Therapist
Baylor University Medical Center
Dallas, TX
gposkey@sbcglobal.net

Occupational Therapy in Health Care™
a journal of contemporary issues

Editor:
Anne E. Dickerson, PhD, OTR/L, FAOTA
Professor and Chair
Department of Occupational Therapy
School of Allied Health Sciences
3305 Health Sciences Building
East Carolina University
Greenville, NC 27858-4354
Phone: 252-744-6190 • Fax: 252-744-6198
dickersons@ecu.edu

July 27, 2007

Gail A. Poskey
8937 Liptonshire Drive
Dallas, TX 75238

Dear Gail:

Your manuscript **#221** *Shaken Baby Syndrome: A Program Evaluation of a Parent Education Class* has been received and sent out for review. Please use your manuscript number in any further correspondence.

Thank you for your contribution and I will forward you the comments when received.

Sincerely,

Anne E. Dickerson, PhD, OTR/L, FAOTA

August 18, 2007

Joy D. Osofsky, PhD
Division of Child Psychiatry
Louisiana State University
Health Sciences Center
1542 Tulane Avenue
New Orleans, LA 70112-2822

Dear Dr. Osofsky,

I have attached to this email transmission a copy of a submission of my original manuscript "Listening to their Voices: Parents' Perspectives on Infant Crying" for review to the *Infant Mental Health Journal*. I have also attached the Title/Cover Sheet and my cover letter.

This manuscript is not currently, nor has it been submitted to any other journal for review or publication.

My address and email is listed below for any future correspondence, and please let me know if you require any additional information.

Thank you very much for considering my work and I look forward to your comments.

Sincerely,

Gail A. Poskey, MOT, OTR
8937 Liptonshire Drive
Dallas, Texas 75238
(214) 503-1566
gposkey@sbcglobal.net

[redacted]

IMHJ

Fri, 24 Aug 2007 14:16:44 -0500

"Marques, Laura M." <lmarq1@lsuhsc.edu>

gposkey@sbcglobal.net

We have received your manuscript "Listening to Their Voices: Parents' Perspectives on Infant Crying" and are sending it out for review. It has been given the manuscript number MS#27-047. Please refer to this number in all future correspondence.

Thanks,
Laura

September 5, 2007

Helene Polatajko, PhD, OT(C), OT Reg. (Ont.), FCAOT
Editor, *OTJR: Occupation, Participation and Health*
Department of Occupational Science and
Occupational Therapy
University of Toronto

Dear Dr. Polatajko,

I have attached to this email a copy of a submission of my original manuscript "Exploring Co-Occupations: Parents' Response to Infant Crying" for review to *OTJR: Occupation, Participation and Health*. I have also attached two additional documents including the cover letter and the title page as outlined in the guidelines.

This manuscript is not currently, nor has it been submitted to any other journal for review or publication. I will fax the signed copyright form to you tomorrow morning.

I have also included below the author information as requested:

Gail A. Poskey, MOT, OTR – Senior Occupational Therapist at Baylor University Medical Center, 3500 Gaston Avenue, Dallas, TX 75246 (E-mail: gailp@baylorhealth.edu). Ms. Poskey is currently a doctoral candidate at Texas Woman's University.

Thank you very much for considering my work and I look forward to your comments.

Sincerely,

Gail A. Poskey, MOT, OTR
8937 Liptonshire Drive
Dallas, Texas 75238
(214) 503-1566
Fax: (214) 820-7741
gposkey@sbcglobal.net

AOTF The American Occupational Therapy Foundation

OTJR: Occupation, Participation and Health
Editor's desk

September 17, 2007

Gail A Poskey, MOT, OTR
Senior Occupational therapist
Baylor University Medical Center

Dear Gail Poskey:

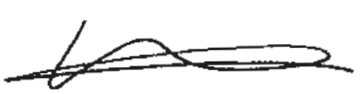
Re: Exploring Co-Occupations: Parents' Response to Infant Crying

Thank you for submitting your manuscript for consideration for publication in OTJR. The manuscript is appropriate to the aim and scope of OTJR and thus is accepted for review. The manuscript will be sent to two reviewers for their evaluation of the scholarliness of the manuscript and its appropriateness for publication in OTJR. Once the reviews are in we will be in touch to advise you of the outcome. You can anticipate that this process will take approximately 8-10 weeks. Please refer to your manuscript as No. HP-07-38 in all future correspondence.

Please send your signed copyright assignment form to us by email to otjr.editor@utoronto.ca or by fax c/o OTJR Editor at 416.946.7102.

Thank you for submitting this manuscript to the *Occupational Therapy Journal of Research* (OTJR).

With best wishes,



Helene J. Polatajko, PhD, OT (C), OT Reg. (Ont.), FCAOT
Editor, OTJR: Occupation, Participation and Health
Department of Occupational Science and Occupational Therapy
Rehabilitation Sciences Building
University of Toronto
160-500 University Avenue
Toronto, Ontario
M5G 1V7
CANADA

TEL. 416.978.5936
FAX 416.946.7102
otjr.editor@utoronto.ca