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The Experience of Foster Families of Cocaine-Exposed Infants

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LOYOLA UNIVERSITY OF CHICAGO

THE EXPERIENCE OF FOSTER FAMILIES OF COCAINE-EXPOSED INFANTS

A DISSERTATION SUBMITTED TO THE FACULTY
OF THE GRADUATE SCHOOL IN THE
SCHOOL OF NURSING
IN CANDIDACY FOR THE DEGREE OF
DOCTOR OF PHILOSOPHY
SCHOOL OF NURSING

BY

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CHICAGO, ILLINOIS

JANUARY, 1995

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To the foster families who took time out of their busy lives to participate in these interviews. To the families who support them and to the individuals and agencies struggling to help children grow up. And to my husband Jim, and children Clark, Matthew, Nora and Ryland who supported me during this work.

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CHAPTER 1

INTRODUCTION

The use of illicit drugs by childbearing women is increasing with alarming frequency. Some estimates indicate that as many as 5 million women of child bearing age are using illicit drugs (US-GAO-HRD-90-138,1990). There is an obvious impact of the use of these drugs on children born to these women. One of the most used drugs is cocaine, either smoked ("crack") or sniffed through the nose.

Current estimates of the number of children born with cocaine exposure range from 100,000 per year to 375,000 per year depending on the source of the report (US-GAO-HRD-90-1990). Currently, accurate estimates of exposure are unavailable, as most projections are based on information from non-representative regional samples. In addition, epidemiologists believe reasonable estimates of incidence may be impossible to obtain because of ethical and legal problems associated with accurate reporting (Chasnoff, Landress & Barrett, 1990).

Significant modifications in the health care system have resulted from increased numbers of exposed infants. Because these infants are more likely than others to be born prematurely and small for gestational age, they require a significantly greater share of scarce health resources than other populations of children. In addition, the life styles of their parents frequently complicate access to the health care system. Thus, longer hospital stays with greater, more expensive technological interventions

are required. Babies who cannot return to their drug abusing families may stay in costly tertiary medical centers because the family cannot manage even minor health care interventions at home. Because many of the babies are born too early, they require interventions such as ventilators, extremely expensive drugs such as surfactant, and high tech monitoring. The GAO (1990) study noted that the median charge for drug-exposed infants at one hospital was \$5,500 while the charge incurred by nonexposed infants averaged \$1,400. Most of this care is underwritten by the hospital and the government because the drug abusing families have no medical coverage. This type of medical intervention depletes even the most comprehensive insurance coverage.

Many hospitals have also experienced an emerging phenomena, the "boarder baby". "Boarder babies" are infants that cannot be discharged in spite of the fact that their diagnosis no longer indicates a need for hospitalization. The course of disease in these children is complicated by an emergent factor, a social diagnosis that requires extended hospitalization. Because parents are unable or unwilling to care for these infants at home, placement with relatives or foster parents must be arranged. For a significant number placement cannot be secured. The GAO (1990) predicts that by 1995, 553,000 children will be in foster care. Most of this increase in demand for foster placement is due to the effects of one drug-cocaine (Soliday, McCluskey-Fawcett & Meck, 1994). The costs of the foster care to our society are high. The cost of 1 year of foster care for 1,200 infants in the GAO (1990) study was \$7.2 million dollars.

Once a foster home is found, foster parents struggle to adequately care for the children with little knowledge of their prenatal and neonatal history. Foster families must care for children in an environment where little is known about their postnatal development and where the popular press warns of the impact of "crack babies" on the society. Research indicates that cocaine-exposed infants may have more medical needs than non-exposed infants (Oro & Dixon, 1987). Although few studies have conclusive results beyond infancy, several reports of infant behavior suggest that cocaine exposed infants may have behavioral results enduring beyond infancy (van Baar, 1990). Cocaine-exposed infants may also exhibit mental and physical developmental delays (Chasnoff, MacGregor, Dirkes & Burns, 1989, Rodning, Beckwith, & Howard, 1989). Foster families choosing to care for drug exposed infants and children may have a unique parenting experience due to the effects of the drug exposure on the infant.

One study of Black children in foster care also indicated that Black infants of drug abusing parents were more likely to be in foster care longer and less likely to ever be returned to their biological parents (Soliday, McCluskey-Fawcett, & Meck, 1994). These infants may remain in foster homes longer than the foster parent predicts at the time of placement. Foster families are often responsible for managing these children during critical developmental periods.

Stories of foster families frustrated with the social services system often appear in the media. Families report that they have poor access to services and little or no voice in decisions about the children they are fostering. In the future more and

more children exposed to drugs will require foster family placement, yet the foster family perspective has not been heard. This study was designed to address this deficit in our knowledge about the experience of parenting cocaine-exposed infants. The research question guiding this study was: "What is the experience of foster families of cocaine-exposed infants?" In light of the paucity of current knowledge about the phenomenon, a qualitative approach was selected.

CHAPTER 2

REVIEW OF THE LITERATURE

A comprehensive analysis of the literature on cocaine-exposed infants was conducted to examine the effects of cocaine exposure during prenatal development. This literature was also examined to determine the effects cocaine exposure might have on the infant developing in the foster family environment. The literature on foster families of drug exposed children was also surveyed to determine the extent of existing research on the subject. The literature review used the following search terms: **cocaine and infants, crack babies, cocaine exposure, cocaine and children, addictions and children, foster family and foster families and drug-exposed infants**. The databases used for this analysis included: Medline, Medlars, and the Humanities and Social Sciences Index. The search years included 1980-1994.

Approximately 150 articles were examined for possible inclusion in the review of the literature. Articles included were: original research reports, research reports examining findings providing syntheses of other reports, and case studies. The primary purpose of the analysis was to synthesize a model of the effects of cocaine exposure on the infant and to determine the present state of knowledge about the experience of foster parents caring for these babies. For this reason, reports of the pharmacology and incidence and prevalence of cocaine exposure were not included in the analysis of the review of the literature.

Thematic analysis was used to analyze the data. Each investigation was evaluated for conceptual themes and methodological limitations. There were not enough studies on foster families of drug-exposed infants to include in the analysis so these were reported individually. Initially, the data on cocaine-exposed infants were organized into the thematic categories: perinatal, teratogenic, fetal and neonatal. Upon closer examination of the data, the categories were collapsed into perinatal and neonatal effects due to conceptual overlap. To assure replicability the analytic process was conducted by the primary investigator and a perinatal nurse expert. Debate was used until consensus was achieved.

Effects of Cocaine Exposure in Infants

A descriptive summary of the literature is provided in Appendix 1. The major salient themes relevant to the effects of cocaine exposure on the infant were: 1) effects could be organized according to the time that they presented (perinatal or neonatal); and 2) effects were primarily related to the effect of increased blood velocity and compensatory responses. Developmental sensitivity of the fetus and dose dependent response were revealed as major predictor concepts. Many of the neonatal sequelae of cocaine exposure are due to the effects of increased intrauterine blood flow and blood vessel constriction due to a dose related effect of cocaine. The stage of development during which exposure occurred is proposed as the major determinant of expression.

Perinatal Effects

Both methodological concerns and salient concepts were identified in the

analysis. The methodological concerns limit the credibility and trustworthiness of the analysis.

Methodological Concerns

Although many studies were reported, use of controls for age, parity, and socioeconomic factors was minimal. Many of the reports were case studies with scant attention to the prenatal, physical and social environment of the infant.

Salient Themes

Pregnant cocaine users have an increased probability of experiencing obstetrical complications such as abruptio placenta (Bingol, Fuchs, Diaz, Stone & Gromisch, 1987; Chasnoff, Burns & Burns, 1987). Hoskins, Friedman, Friedan, Ordorica & Young (1991) found placental abruption in cocaine abusing patients by using serial dopplers. Many studies also report an increased incidence of preterm labor and birth (Hoskins, et al, 1991; Mastrogiannis, Decavalas, Verma, & Tejani, 1990; Chasnoff, Burns & Burns, 1987; Cherukuri, Minkoff, Feldman, Parekh & Glass, 1988; Fulroth, Phillips & Durand, 1989; & MacGregor, et al, 1987). Chasnoff, Griffith, et al, (1989) and Chasnoff, Burns, Schnoll & Burns (1987) found that spontaneous abortion, preterm labor and preterm birth were increased when high doses of cocaine were taken late in pregnancy. Intrauterine death was also reported by a number of investigators (Burkett, Yasin & Palow, 1990; Neerhof, MacGregor, Retzky & Sullivan, 1989). Stillbirth has also been reported with increased frequency following cocaine exposure (Burkett, Yasin & Palow, 1990).

Fetal and Neonatal Effects and Methodological Concerns

Many studies were reported, while use of controls for age, parity, and socioeconomic factors was minimal. Investigators relied on non longitudinal approaches, nonrandomized designs, small sample size and gave little attention to variable selection. Psychometric characteristics of measurement tools were seldom discussed making generalizability of study findings a concern.

Salient Themes

Fetal and neonatal effects due to abnormal blood flow, constriction of vessels and resulting ischemia were identified and included: 1) necrotizing enterocolitis (Czyrko, DelPin, O'Neill, Peckham & Ross III, 1991; Porat & Brodsky, 1991; Telsey, Merrit & Dixon, 1988, Hoyme, et al, 1990); 2) ophthalmologic abnormalities (Dominguez, Vila-Coro, Slopis & Bohan, 1991; Teske & Trese, 1987); Isenberg, Spierer & Inkelis, 1987; 3) limb reduction deficits (Hannig & Phillips III, 1991; Hoyme, et al, 1990); 4) cardiovascular abnormalities (Lipshultz, Frassica, & Orav, 1991; van de Bor, Walther & Ebrahimi, 1990; Little, Snell, Klein & Gilstrap, 1989; Bauchner, et al, 1988); and, 5) brain abnormalities including intraventricular hemorrhage (Burkett, Yasin & Palow, 1990; Dominguez, et al, 1991; Neuspiel et al, 1991; Little & Snell, 1991; Gingras, O'Donnell, & Hume, 1990; Gingras & Weese-Mayer, 1990 (animal study); Church & Overbeck, 1990 (animal study); Henderson & McMillen, 1990 (animal study suggesting dose related differences); Dixon & Bejar, 1989; Dixon, 1989; Anday, Cohen, Kelley & Leitner, 1989; Chasnoff, Bussey,

Savich, & Stack, 1986; Chasnoff, Lewis & Squires, 1987; Shih, Cone-Wesson & Reddix, 1988). One investigation (van de Bor, Walther & Sims, 1990) reported increased cerebral blood flow associated with even low doses of cocaine exposure possibly explaining many of the brain abnormalities identified. Fetuses and neonates are reported to exhibit the effects of cocaine teratogenicity including urogenital abnormalities (Chasnoff, Chisum & Kaplan, 1988; Chavez, Mulinare & Cordero, 1989; Greenfield, Rutigliano, Steinhardt & Elder, 1991).

Many investigators documented an increased incidence of small for gestational age (SGA) and/or low birth weight infants following cocaine exposure (Hoskins, et al, 1991; McCalla, et al, 1991, Frank, et al, 1990; Zuckerman, et al, 1989 (related to dose of cocaine and stage of pregnancy when exposed); Mastrogiannis, Decavalas, Verma & Tejani, 1990 (less problems with chronic vs. acute usage); Habel, Kaye & Lee, 1990; Burkett, Yasin & Palow, 1990; Saylor, Lippa & Lee, 1991; Chasnoff, Griffith, et al, 1989 (related to dosage taken and stage of pregnancy); Cherukuri, et al, 1988; Chouteau, Nemerow & Leppert, 1988; Dixon, 1989; Fulroth, Phillips & Durand, 1989; Little Snell, Klein & Gilstrap, 1989; MacGregor, et al, 1987, Neerhof, MacGregor, Retzky & Sullivan, 1989; Oro & Dixon, 1987; Ryan, Ehrlich & Finnegan, 1987).

Several researchers found physical effects of cocaine exposure in addition to small size. These physical manifestations include: microcephaly (Hadeed & Siegel, 1989; Fulroth, Phillips & Durand, 1989; Oro & Dixon, 1987; Ryan, Ehrlich & Finnegan, 1987) and low osteocalcin (suggestive of skeletal problems) (Rico, Costales,

Cabranes & Escudero, 1990).

A group of investigations identified alterations in behavioral state in cocaine exposed infants (Burchfield, Graham, Abrams, & Gerhardt, (animal studies), 1990; Gingras, O'Donnell, & Hume, 1990; Burns, Chethik, Burns & Clark, 1991; Chasnoff, Burns, Schnoll & Burns, 1987). However, one recent study (Neuspiel, Hamel, Hochberg, Greene & Campbell, 1991) found no differences in behavioral states in cocaine exposed infants when compared with similar infants without cocaine exposure. Notably, this study employed reliable and valid measures, the Brazelton Neonatal Behavioral Assessment Scale (NBAS) and the Nursing Child Assessment Feeding Scale (NCAFS) to examine possible differences between groups.

Two studies described an increase in meconium staining of amniotic fluid in the presence of cocaine exposure (Little, Snell, Klein & Gilstrap, 1989; Chasnoff, Burns & Burns, 1987). These results suggest cocaine exposure may cause stress before birth.

Another group of studies suggests neurobehavioral expressions of cocaine exposure including: 1) delay in mental development,(primarily related to language) (vanBaar, 1990); 2) developmental delay (Dominguez, Vila-Coro, Slopis & Bohan, 1991); 3) poor tone (Saylor, Lippa & Lee, 1991; Oro & Dixon, 1987); 4) increased jitteriness (Parker, et al, 1990, Oro & Dixon, 1987); 5) poor feeding (Oro & Dixon, 1987); 6) abnormal sleep patterns (Oro & Dixon, 1987); and, 6) seizures related to dose of cocaine (Rivkin & Gilmore, 1989; Bateman & Heagarty, 1989).

Many interventions such as apnea monitoring and environmental stimuli control

have been suggested for cocaine-exposed infants. However, empirical bases for these programs are unavailable. For example, although apnea has been reported to be decreased in cocaine-exposed infants, most intervention programs for this population require home apnea monitoring. Studies attempting to link cocaine exposure with SIDS (Sudden Infant Death Syndrome) have demonstrated variable results. An increased occurrence of SIDS was suggested by one study in animals (Gingras & Weese-Mayer, 1990), one study of fetuses (Gingras, O'Donnell & Hume, 1990) and one study of infants (Chasnoff, Hunt, Kletter, & Kaplan, 1989). However, one well controlled investigation with a more robust sample (Bauchner, et al, 1988) found no increased risk.

The small sample size of many of these studies, coupled with non-randomized designs, suggests the need for longitudinal study of the effects of cocaine exposure in utero.

Foster Families of Cocaine-Exposed Infants

The review of the literature related to foster parenting cocaine-exposed infants revealed only one study, published in 1994 (Soliday, McCluskey-Fawcett, & Meck, 1994). The sample included 18 foster mothers of drug-exposed toddlers (age 12-30 months) and 11 foster mothers of non drug-exposed toddlers. The study found no group differences in parenting stress and satisfaction, while both groups of foster mothers reported high levels of social support.

Several studies about the experience of foster families of children with HIV were found (Dennis, 1992, Groze, McMillen & Haines-Simeon, 1993, Taylor-Brown,

1991). Many children with HIV are from families of origin who abuse drugs. Groze, McMillen & Haines-Simeon (1993), found that foster families of children with HIV felt that the experience was very rewarding. This study also found that families choosing to foster parent HIV positive children frequently had some sort of previous experience with HIV, a belief that they had something to offer the children and a personal desire for fulfillment (Groze, McMillen & Haines-Simeon, 1993). The study also found that families had not felt that their input was recognized in the social service system, particularly the judicial system. Parents sometimes felt that they had to fight for rights for their foster children including medical care, food subsidies and in one case, even burial after the child died (Groze, McMillen & Haines-Simeon, 1993).

Another study of foster families of children with disabilities found that many foster families were recruited by advertising campaigns and that 39% of the other families in their study had some experience with disabled people through work or personal contact prior to parenting a foster infant (Siegel & Roberts, 1989).

Little is known about the experience of families who foster cocaine-exposed infants. A great deal more work needs to be done before the needs of these families are truly understood.

Theoretical Framework

Because of the paucity of information in the literature about the experience of families who foster cocaine-exposed infants, no model is available to direct this investigation. In order to generate a model, a qualitative methodology was employed

to answer the research question.

In addition, an integrative review of the literature focused on the impact of cocaine exposure on infants was conducted and two models were generated: one represents the high dose effects of cocaine exposure (Figure 1) and the other the effects of cocaine that may lead to preterm birth (Figure 2).

Much of the research conducted on cocaine-exposed infants has been done without controls for dose or stage in pregnancy when cocaine was used. The few studies which have had such controls have indicated that the effects of cocaine are dose related and related to the stage in pregnancy when the Mother used the drug. The high dose related effects (Figure 1) include: placental abruption, preterm labor, decreased uterine blood flow, intrauterine growth retardation, preterm birth, spontaneous abortion and fetal demise.

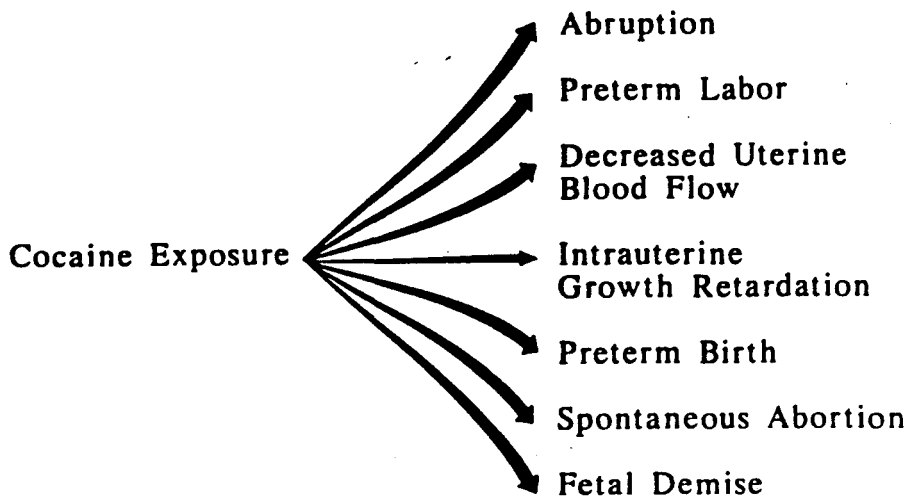


Fig.1. Cocaine Use: Prenatal High Dose Related Effects

Many researchers have associated preterm birth and low birth weight with cocaine exposure. Figure 2 provides a graphic representation of the relationship between cocaine exposure and the incidence of preterm birth.

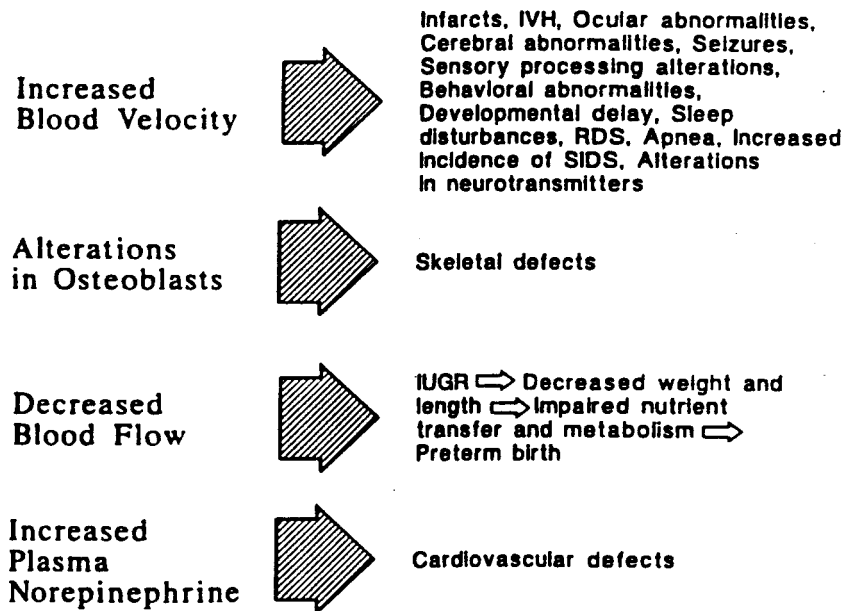


Fig.2. Effects of Moderate and Repeated Low Dose Cocaine-Exposure

In a study of four hospitals in 1989-1990 by the GAO (US-GAO-HRD-90-138,1990) drug exposed infants represented 30-50% of all infants who were born prematurely. These infants incurred from 100% to 400% higher hospital charges than

non-cocaine exposed infants (US-GAO-HRD-90-138,1990).

Many researchers have confirmed the infant's ability to exert an influence on their caregiver (Stern, 1974, Brazelton, 1974; Barnard, 1978). The preceding review suggests that the neonatal effects of cocaine exposure may place an exposed infant at risk for optimal caregiver interactions. Brazelton (1984) posits at least two sources of vulnerability that contribute to the risk of failure in developmental outcome: the baby's own organizational system and capacity for growth (both central nervous system and autonomic system); and the capacity of the environment (usually represented by the parents) to adjust to and nurture the at-risk infant in ways that are developmentally appropriate.

Observing and Investigating Cocaine-Exposed Infants and Their Caregivers

The short term physical and neuro-behavioral effects of cocaine exposure in infants are frequently reported in the literature. While these are of great interest to nursing, there is also a need to describe the long term behavioral and developmental effects of cocaine exposure.

The Brazelton Neonatal Behavioral Assessment Scale (BNBAS)(Brazelton 1974), a psychometrically reliable and valid measure, has been used to evaluate normal newborn behavioral responses. Differences in infant behavior related to drugs, maternal diabetes, neonatal jaundice and infant nutritional status have been documented using this tool (Anderson, 1986). The BNBAS has also been used to evaluate cocaine-exposed infants (Chasnoff, Burns, Schnoll & Burns, 1957, Chasnoff, Griffith, MacGregor, Dirkes & Burns, 1989, Neuspiel, Hamel, Hochberg, Green &

Campbell, 1991). One limitation to the BNBAS is that it was designed for use on full-term infants only up to 28 days of life. Cocaine-exposed infants are frequently premature and may exhibit effects of cocaine exposure far beyond 28 days. Free, Russell & Mills, (1989) report on the use of the Nursing Child Assessment Satellite Training tools (NCAST), physical exam, and developmental assessment, on children with polydrug exposure (most often due to the combination of cocaine with alcohol). The findings indicate a need to refine behavioral measures for cocaine-exposed infants.

The lack of tools designed for the assessment of cocaine-exposed infants affirmed the need for qualitative observation of these infants and caregivers in order to generate a model to organize further investigation. Qualitative research is ideal for describing the experience of these foster families in their home environment as they parent cocaine-exposed infants. Therefore, this study was designed to answer the question, "What is the experience of foster families of cocaine-exposed infants?"

CHAPTER 3

METHOD

The study of the experience of foster families caring for cocaine-exposed infants used the format of naturalistic inquiry developed by Lincoln and Guba (1985). The plan for naturalistic inquiry which involves ten steps is explained in detail relative to this investigation. The naturalistic paradigm is appropriate for this type of study because, as indicated in Chapter 2, there is a paucity of previous research on the subject.

Step 1: Determining a Focus for the Inquiry

Focusing the inquiry serves two major purposes. It establishes the boundaries for the study and determines whether new information discovered through the study will be included or excluded. It allows the researcher to make decisions about retaining or discarding information (Lincoln and Guba, 1985). For the purpose of this study, foster families, licensed by the State of Illinois, caring for cocaine-exposed infants, ages zero to two and one-half years of age, were eligible for inclusion in the study. The determination of whether or not a baby was cocaine-exposed was made by the agency referring the child to the State of Illinois. Foster families who take babies with unknown drug exposure or drug exposure known not to be cocaine were not included although several families had, in the past, foster parented many infants with multiple and unknown drug exposures. This study did not differentiate between

babies known to be exposed to cocaine only and babies with multiple drug exposures, including cocaine. This was due to the difficulties associated with determining drug exposures the child has undergone and the potential for alcohol as well as polydrug use confounding the measures. Mothers frequently do not report drug exposure due to fear of prosecution. Most drug screening of newborns only determines drugs the mother has ingested in the 72 hours preceding birth. Therefore, reports of the number of drug-exposed infants is likely to be much larger than current statistics indicate (US-GAO-HRD-90-138,1990). Foster families not formally licensed by the State of Illinois were not included in the study.

Ethical Considerations in This Design

The subjects in this research inquiry were assured of the highest level of confidentiality of their responses to interviews. The consent form was given to each participant so they could call the primary investigator even if they decided not to participate after the interview was completed (See Appendix 2).

As the results of this study were reported, care was taken to assure that families were not individually identifiable. In addition, families were assured that they could leave the study at any time and could refuse to answer questions which they found objectionable. Family members were also assured that they could have responses erased if after answering a question they decided they did not want their response included. No families ever requested not to be included or to have certain responses erased. The family was given the primary investigator's phone number if they had any questions or concerns about the study after the interview. None of the

participants contacted the investigator after the interview to request being dropped from the study.

Step 2: Determining Fit of Paradigm to the Focus

The naturalistic paradigm was chosen as the appropriate paradigm for the study of the experience of foster families caring for cocaine-exposed infants for several reasons. At the present time, only one research report has been published on foster families caring for cocaine-exposed infants. There are several examples of studies of medical foster families with children with special needs and other papers on the behavioral and developmental characteristics of babies of cocaine abusing mothers (Groze, McMillen & Haines-Simeon, 1993, Gurdin & Anderson, 1987, Rendon, Gurdin, Bassi & Weston, 1989, Siegel & Roberts, 1989). A review of the literature found only one paper linking foster families and cocaine-exposed infants (Soliday, McCluskey-Fawcett & Meck, 1994). Because of the dearth of research, descriptive work can establish the need for further research. The naturalistic paradigm is also appropriate for establishing priorities for future research including qualitative studies. Because the research is conducted in the natural (in this case, home) setting, the research can establish the priorities of the families. The foster families parenting the cocaine-exposed infants could identify the concerns most appropriately.

Step 3: Determining the "Fit" of the Inquiry Paradigm to the Study

Naturalistic method, as described by Lincoln and Guba (1985) became the theoretical structure guiding the development of the model. Data were analyzed to allow themes to emerge as they were presented in the natural environment.

Step 4: Determining Where and From Whom Data Will Be Collected

The recommended sampling approach in the naturalistic paradigm is maximum variation sampling. The widest possible variety of cases were selected to provide a broad range of information (Lincoln & Guba, 1985). Several considerations in selecting a sample, described by Lincoln & Guba (1985), guided the selection of the sample for this study.

Providing for Identification of Initial Elements

Initially, families were referred to the investigator by an ad placed in the Chicago Parent, a monthly publication distributed free to Chicagoland hospitals, day care agencies, YMCAs and other social service agencies, pediatricians' offices and community locations. This yielded two potential interviews, one was completed using this source. Many foster families called the investigator but their children did not fit the criteria for inclusion in the study. These inquiries did indicate that a great many foster families wanted to participate in research and wanted their story to be told. As each family was interviewed, they were asked to identify other foster families they knew who may have had the same or a "different" experience than their own in caring for a cocaine-exposed infant. A second method that yielded several families was contact with social service agencies placing drug exposed infants for foster care. Lutheran Social Services provided access to many families. Other families were referred through professional contacts. Several colleagues were aware of foster families in the community and contacted the families asking their permission for the primary investigator to contact them.

Providing for Orderly Emergence of the Sample

Every attempt was made to complete interviews, compare data and exhaust the information available from each family before moving on to the next family. All family members who were available and involved in the care of the cocaine-exposed infant were interviewed. In all but two of the families, the male caregivers were not present during the interview.

Providing for the Continuous Refinement or Focusing of the Sample

Lincoln and Guba (1985) write that as the investigation proceeds, and as more and more interview data is added to the analysis, certain major themes begin to emerge. As these themes emerge, the inquiry begins to focus on adding more data to each of the major themes. This was accomplished through the constant-comparative method of method of data analysis described by Glaser and Strauss, (1967). Each interview was transcribed and analyzed for emergent themes. As new interviews were added, major themes became more defined. As the final interviews were analyzed, additional data was added to the previous themes and no new major themes emerged.

Providing for Termination

The process of interviewing was terminated once saturation of the data categories occurred. This was determined when several successive interviews no longer revealed new themes, and at the point that the primary investigator, policy board (a group of experts providing guidance to the inquiry) and peer debriefer agreed that no substantive new themes were occurring.

Step 5: Determining Successive Phases of the Inquiry

In accord with Lincoln and Guba (1985), three successive phases of naturalistic inquiry were followed in this study.

Phase 1

Phase 1 consisted of the first two interviews. The interviews were conducted with the following question, "Tell me what it has been like to be the foster parent(s) of _____ (child's name)". This very broad and open-ended question helped the investigator focus and develop a more structured approach to questioning.

However, this question always remained the first question asked. This was to assure that the family had the opportunity to tell their story, with their words, and their primary concerns in foster parenting.

Phase 2

Phase 2 is the phase of focused exploration. At the conclusion of Phase 1, the first two interviews were analyzed and a more formal interview schedule was developed with the assistance of the policy board (a group of experts chosen to help guide the primary investigator). The policy board also served as the dissertation committee and consisted of a researcher skilled in qualitative methods and childbearing families, a researcher skilled in concerns of children and families and a researcher skilled in issues of childbearing women and infants. This group helped the investigator develop a more structured interview schedule while retaining the initial unfocused question (See Appendix 3). The focused interview schedule allowed the

investigator to obtain information about the emergent themes. However, it was not followed rigidly. The purpose of the naturalistic inquiry is to determine themes emerging from the sample, therefore, responses were rephrased and followed up. If a family indicated a concern, problem or thought about foster parenting, their response was investigated even if it deviated from the original question. The policy board also provided advice about securing the sample, negotiating entry into settings and dealing with concerns that occurred during the investigation. For example, during phase 2, the primary investigator encountered a number of families living in high crime areas and in apartments with little or no security offered to the investigator at arrival or departure. The investigator discussed this problem with the policy board. All agreed that enough data had been gathered from this type of respondent and that the investigator should proceed in neighborhoods offering more security and safety to the investigator.

Phase 3

Phase 3 is the "member check" phase (Lincoln and Guba, 1985). Phase 2 data was analyzed and taken back to the informants for confirmation that the investigator's interpretations accurately represented the responses and thoughts of the informants. In this investigation, the responses were confirmed through the use of question probes during the interview. Because the primary investigator was the only data collector, statements could be clarified at the time of the interview. The investigator rephrased and reworded responses during the interviews until the investigator and the foster family were satisfied that meaning was understood. The investigator also had the

phone numbers of all respondents and had permission to call if information was unclear during transcription and analysis. Member checking with one informant who had foster parented 150 drug-exposed infants was used to verify themes from all interviews.

Step 6: Determining Instrumentation

Lincoln and Guba (1985) emphasize the need to set up data collection teams when designing naturalistic inquiries. However, for this study, funding sources and availability of investigators trained in the naturalistic method made a data collection team unfeasible. Interviews were tape recorded and transcribed verbatim. Policy board members assisted in the analysis and interpretation of data. In the first phase of the investigation, policy board members suggested additional questions or lines of inquiry and during subsequent phases they and the peer debriefer assisted the investigator in validating themes identified in the transcripts. The peer debriefer was a pediatric nurse with a nursing doctorate (ND) who had conducted naturalistic research. The peer debriefer helped code some of the data, assisted with determining themes and assisted in clarifying when all major themes had emerged. She, along with the policy board determined when the investigation could be concluded (Lincoln & Guba, 1985).

Step 7: Planning Data Collection and Recording Modes

The interviews took place in the homes of the foster families. One foster mother chose to be interviewed in a coffee shop because her child had just had surgery and the interview was conducted late at night so she could be free from

parenting responsibilities during the interview. Because such "natural" settings were used, consent was obtained from family members for tape recording of the entire interview. High quality tape recorders with built in microphones were used. The standard size cassette player was determined to be more useful than the micro or mini cassette player because tapes could be played back on a variety of tape players, and could be tested for quality in a car tape player immediately after the interviews. One interview had to be discarded due to high ambient noise. In all cases, the interview was conducted in the quietest possible place in the house. Field notes were included on an audio tape immediately after each interview. The field notes contained the investigator's impressions of the interview, the setting and an overall impression of the child (children). The investigator also audio recorded impressions of the home environment as a way of adding data to the investigation.

Step 8: Planning Data Analysis Procedures

The constant comparative method was used to analyze data obtained in the interviews. The tape recorded interviews were transcribed verbatim and analyzed through the use of WordPerfect 5.1 and the line numbering and search commands. The analysis began with the first interview and proceeded with successive interviews until saturation of themes occurred. Lincoln and Guba (1985) are very careful to point out that data analysis begins as the first data is obtained and emerges as more data is collected and analyzed. Themes in the first two interviews were identified line by line. 50 - 100 themes emerged per transcript. After consultation with the peer debriefer and the policy board, themes were collapsed into the following three broad

categories: Infant, Foster family and Social System. Saturation of the data and thick description yielded saturation of the data set after interviews. The peer debriefer coded some of the data with the principal investigator utilizing the method of Miles and Huberman (1990). This established dependability in the data coding.

Step 9: Planning the Logistics

Agents

This design was implemented by the primary investigator. The primary investigator has 15 years experience as a pediatric nurse in both tertiary and rehabilitation settings. She was a research assistant on a study of families of children with hemophilia and worked with a research team investigating negotiation between nurses and families to determine family wishes for care delivery during a child's hospitalization. The primary investigator is certified in the administration and use of the Nursing Child Assessment Satellite Training (NCAST) tools including the Home Observation for Measurement of the Home Environment (HOME). The peer debriefer is a pediatric nurse experienced in qualitative research methodology. The peer debriefer assisted the primary investigator in coding the data.

Orientation and Overview

The initial phase of the project was completed in two months. Although the investigator had negotiated entry into one site, publicity and bureaucratic constraints prevented access to foster families from that site. The ad in Chicago Parent yielded additional families and contact with other agencies and colleagues.

Focused Investigation Phase

During the focused investigation phase, the researcher concentrated on interviewing as many different types of foster families as possible to exhaust all possible categories of data. This phase was the lengthiest and lasted approximately 5 months. The policy board and peer debriefer were available during this phase to help the researcher verify that saturation occurred in data collection.

The Audit Phase

The audit phase consisted of the member check and the external audit (Lincoln & Guba, 1985). The member checking was conducted during the interviews and with one foster mother after all data analysis was completed. During the interview, probing questions were used to clarify response to the initial questions. This served as member checking by clarifying the meaning of the response to the satisfaction of the respondent. After data analysis, member checking was used to determine if themes determined to be representative of several respondents were actually representative. The external audit was also conducted during this phase to assure dependability and confirmability. The external auditor examined the research design, had access to audiotapes, transcriptions and data analysis as well as taped field notes and records of interactions with the policy board and peer debriefer. The external audit was conducted by a doctoral candidate in nursing who had experience in qualitative designs (See Appendix 4). This phase lasted approximately 2 months. This phase was more lengthy than usual because the primary investigator had moved out of state and could not give up raw data, transcripts and displays of thematic analysis until the policy

board was satisfied with the organization of the results of the investigation.

Step 10: Plan for Trustworthiness

The plan for trustworthiness is the most important part of the naturalistic design. Techniques which establish trustworthiness can be summarized as fitting within four criterion areas. These criterion are: credibility, transferability, dependability, and confirmability. The study design included techniques for trustworthiness of the study relating to each of the above criteria.

Credibility is analogous to internal validity in quantitative research. Credibility in this study was established through prolonged engagement in the field. Each interview was conducted in 45 minutes to 1 hour. New families were added to the study until salient themes ceased to emerge. Persistent observation occurred until areas of questioning were exhausted. Many sources were used to get as many types of families as possible into the study. The primary investigator used personal contacts, newspaper ads, and professional contacts to obtain a wide variety of foster families. The policy board also assisted with validation of coding and emergent themes. Other methods for establishing credibility include peer debriefing and member checks. Steps 4 through 9 outline the techniques for establishing credibility in detail.

Thick descriptions also assisted to establish trustworthiness of the study. Transferability was achieved through thick description and is analogous to construct validity in quantitative research. This study provided for thick description through word for word transcriptions of the interviews and through coding agreed upon jointly by the policy board and the peer debriefer. Thick description (Lincoln & Guba, 1985)

allowed the foster family subjects to answer interview questions at length. This allowed themes to emerge from the experience of the foster families rather than from the perspective of the investigator.

An external audit helped establish the dependability of the study. This was accomplished through the audit trail. Dependability was also established by having at least two people analyzing some of the same data to see if the same themes were identified.

Confirmability, which is analogous to external validity in quantitative studies was established through the audit trail. The external audit provided the investigator with an outsider's (presumably unbiased) appraisal of the trustworthiness of the investigation. The results of the external audit are found in Appendix 4.

The reflexive journal helped the investigator set aside biases and see issues and themes that might not be apparent from the interview transcripts alone.

All of the above techniques helped establish the trustworthiness of the study.

CHAPTER 4

RESULTS

Seven families (primarily mothers) were interviewed for this study. Nine children were in the designated age range (2 months to 30 months). The interviews were conducted in Chicago and suburban locations between March and September, 1993. All interviews, except one, were done in the foster family's home. All foster families signed a consent and agreed to audiotaping. An additional eight drug-exposed children who did not fit the study criteria because of age were in foster care in the homes. Some of these families had biological children living in the household, two families had foster children only, two foster mothers were biologically related to their foster children (one was the grandmother and one the aunt) and three had adopted foster children. None of the families had adopted or biological children who were still in infancy. All of the families were licensed by the State of Illinois. All were receiving compensation from the state for foster parenting. All the families were under supervision by a social worker from either the State of Illinois (Division of Children and Family Services) or a private social service agency contracted by the state.

Three major categories of themes emerged during the data analysis: Infant, Foster Family, and Social Systems (See Figure 3).

Infant Themes

PHYSIOLOGIC HEALTH	BEHAVIORAL HEALTH	DEVELOP-MENT	VARI-ABILITY
Growth	Feeding		Respon-siveness
Intercranial Bleeding	Irritability		
Breathing Problems	Vestibular Stimulation Sensitivity		
Immune System Compromise	Tremors		
Skin Problems	Screaming		
Other	Poor Tone		
	Uncontrollable Crying		
	Adaptability		
	Sleep		

Foster Family Themes

Motivation to Parent	Difficulties in Parenting	Functioning of the Nuclear Family	Needs for Support	Advice for Others
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Social Systems Themes

The Family	The Community	The Health Care System	The Social Services System
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Fig.3. Summary of Infant, Foster Family and Social Systems Themes

Information on the experience of foster parents with other drug-exposed children was frequently interjected. Families were frequently unable to separate the

experience of caring for the infant, currently in their home, aged 2 months to 2 1/2 years, from the experience of other cocaine-exposed children in the home at the present or in the past. Each of the themes are described in the following section. Examples of interview content from which the theme emerged are also presented.

Infant Themes

Themes that emerged and coalesced into the category infant included:

Physiologic and Behavioral Health, Development, and Variability.

Physiologic Health

Growth

Several of the infants were born prematurely and/ or were small for gestational age. One mother who fostered many cocaine-exposed infants stated:

And I've also seen that most of the children I've had, they're kind of small, they were born preemie. And three of my six never got off the bottom of the growth chart. They stayed small.

Intercranial Bleeding

A few of the infants were reported to have had intercranial bleeds in the perinatal period.

"Breathing Problems"

A number of infants were reported to have breathing problems at birth.

Yes, he did (have breathing problems at birth). He had to stay in the hospital for a while because he was sick, he was born with drugs in his body. That was why he couldn't go home.

Almost all the infants were on apnea monitors although no incidents of apnea were reported by the foster families.

Immune System Compromise

Another problem that emerged from this study that has not been confirmed in the research literature was immune system compromise. Several parents were caring for infants with compromised immune systems. Most of the parents expressed an awareness of HIV and reported that there was a possibility that the infants might be HIV positive. One mother noted that her child was "no longer HIV positive" but still had low numbers and a "low immune system". Many families reported that they were "almost constantly" dealing with ear infections, upper respiratory infections and lingering colds. One mother said,

This is what I hear from every person I talk to who is taking care of drug-exposed children. There seems to be something wrong with their immune systems.

Other indicators of a compromised immune system such as oral thrush and candida diaper rash were also reported.

Skin Problems

One other health issue that a few families reported that has not appeared in the research literature is skin problems. Most of the mothers have found ways to deal with extremely dry or sensitive skin.

She has some skin problems. Anything with fragrance is a problem although we've found one lotion we can use with her.

Other Physical Problems

One baby had eye surgery and two had heart problems (unspecified by family) one requiring surgical correction. Almost all the infants required physical therapy, and/or occupational therapy. A foster mother described her child's need for therapy

in this way:

Yes, he goes to occupational (therapy) because he had for a little while some trouble with his legs, his left leg is a lot longer than his right, for a while he had some stiffness and we're working with him.

Behavioral Health Themes

Feeding

Several families reported feeding problems. Some of the problems were related to oral motor deficits while others, by family report, were cow's milk allergy, colic, or "sour stomach".

The first baby, she threw up all the time, her feedings were terrible. ...Just from having the children in my home and from talking with other foster Moms, I suspect that a lot of the irritability and the crying that newborns seem to have is just from food. [Same mother describing another infant] So I just switched around with him and he was fine. We just used Nursoy [non cow's milk based infant formula] and the cramping or whatever they call colic and it went away.

Irritability, Vestibular Stimulation Sensitivity, Tremors, Screaming, Poor Tone and

Uncontrollable Crying

A number of behavioral indicators of neurological insult were reported.

Several parents described these behaviors:

Well, like this one, she just screams. And this other one (another child), he will just start crying for no reason.

Dante is a happy baby, but you can tell he has some withdrawal symptoms because he will cry and cry for no reason.

I've had Trudy for six months, since she was a little baby. And she has that screechy scream....when they cry, it's that aggravating cry.

Some families commented on the irritability and sensitivity to touch or vestibular stimulation.

...on one of his bad moods days...You catch hell. You need some real real serious Excedrin, because on one of those days...you catch it. He doesn't want you to touch him, he gets real irritable.

She likes to be held close but not be patted on the back. To burp her, I sit her up and rub her back sometimes. Very gently. I put her on my shoulder, but she just doesn't want anyone to pat on her, not her back, just sit her up, not her behind, nothing. She doesn't like to get her hair brushed, she doesn't like the feel of the brush, even with a soft baby brush.

Families had generally found ways to deal with the irritability. Some of these ways of coping will be discussed in the family themes section.

Adaptability

A few families had parented infants over many months and observed some of the more long term aspects of behavior, such as the infant's adaptability in daily life situations.

We have some friends with kids, Mollie is real forward, she's not shy, she usually scares other kids. She does a lot of hitting, a lot of throwing things, she's starting to play a little better. She does better with older kids. Someone her own age is afraid of her. (A later description of the same child) When eating, she's been real fussy, now she's just beginning to eat. Dinner time is real wild around here around 4-6pm. Mollie does a lot of screaming, then around 7:30 or 8 she goes to bed, she's real good about that. She's always needed a lot of naps or alone time.

Because there are days...I put him in his crib and I put him somewhere he can't hurt himself. There is something that goes off inside his head, he can't help it. It is just something that goes off.

Because they are constantly wanting something, even when they are in the room playing, they want something and they keep coming back to you (the mother).

Sleep

Sleep behavior was reported as a concern by several families. Most families

were able to adjust to sleep problems but some reported that their infants did not sleep through the night or required very little sleep. One mother who had fostered several children said:

She sleeps very well during the daytime, when there is a little bit of noise outside. At night time, when it is very quiet, I hear her moving around almost all night long....She's one of the better kids from exposure that we get.

Another foster mother described the first days with her foster son:

...when Dante came, ooh, those early morning wakeups! He would get so confused, he would wake up late in the evening and then stay up all night long until about 5 in the morning. And I'm like, oh my God, how am I going to last this?

Several other families noted no sleep problems:

She sleeps well. She sleeps all night. But the only time she's cross is when she's teething.

The popular media frequently provided reports about sleep problems in cocaine-exposed infants. Foster families are taught interventions (such as low lighting and no noise) to help cocaine-exposed infants sleep better. However, it is interesting that foster parents in this study did not identify infant sleep behavior as one of their primary problems.

Development

Several of the families had also fostered other drug-exposed children and compared the infant they were currently foster parenting with others.

This baby is nothing like the other baby I had. She's gaining weight, she's really alert...The other baby I had didn't respond this way at all.

(from another Mom) Now, I would like to look at Sara and say she's doing really well and is one of the better kids developmentally than

we've had but I would never tell anyone that there wouldn't be problems.

Other families described the normal aspects of their child's development.

He's a fast learner, he is eager to learn. How can I say it? With some kids, they're not as happy, he is a happy child.

(from another family) And I believe that if there was drugs there, the Lord taken it and its not there now. She's normal, she crawls, she's not handicapped, she's very alert, she notices everything.

Some families described the ways their foster children were developing and commented that their child just wasn't like others, was better.

(question from researcher) Do you think the children have any special needs because of their drug exposure? Mom: I think they have special needs just because they are children.

If you really, really work with him, he is just like any other child, you'd never know he is a drug-exposed child. No, he is developing just fine. As young as he is, they just can't find anything wrong with him, just the occupational (therapy).

One mother who had foster parented over 150 drug-exposed infants summed up the issue this way:

I've heard that they (drug-exposed infants) are screamers and pukers and difficult to get along with. Never are very smart, don't gain weight, maybe look funny. These are all terrible things to say. I'm telling you what I've heard, not what I believe. Most of them are baloney.

Even though many foster families described the normal aspects of their infants, they still worried about the future development of their foster children. Some of the parents believed their infants faced an uncertain future.

...The first year you didn't notice too much but as he got older you saw a lot of behavior problems. You can't tell at first what's wrong with them (drug-exposed infants).

(from another Mom) These things really don't show up on the outside. If you were just looking at him, you would never know (that he was drug-exposed).

One foster mother made a poignant statement:

Well, my children, I compare them to the walking wounded because they look fine. It's the neurological insult they've had that makes it difficult to cope with the things they have to cope with. (One prominent physician) has said that by the time they are 2-3 years old that they're fine. And I really question that. I'm not sure what he means. If he means out of withdrawal, then yes, they are out of withdrawal. But if he means that they are settled for life, they're not.

Variability

Most of the health problems that foster families describe are also confirmed in the literature. However, variability is reported by the foster families. As noted earlier, some infants had feeding problems, others did not. Some infants were irritable, others were not. Some mothers were constantly going to the physician for illnesses, others said their foster infants were healthy.

Nothing (health problems) ever that a doctor would have to give them a shot for. I only have to take them for their regular shots.

(Another Mom) So, my babies is healthy. I take them to Pat at the clinic and she teels me they are healthy babies.

Some children have health problems very likely related to cocaine exposure while other cocaine-exposed children have no recurring health problems. The majority of the infants in this study had polydrug exposure by foster family report.

One foster family noted some of the other potential health issues that may come from a drug abuse environment such as neglect in feeding, clothing and providing security to the infants.

(The three foster children she parented were siblings.) They had enough of being left alone. No one around them, not enough food.

Responsiveness

Infant cues are important to the development of the caregiver-child relationship. Research studies suggest that cocaine-exposed infants often give hard-to-read cues. Once again, variability was found in the reports of families in this study regarding responsiveness. Several mothers described very responsive foster infants:

Nooooo, he wants his bottle and he wants it now (describing an infant who gave clear feeding cues)!...He is a happy child. Now, he has his moods, but some kids, they just aren't as happy as he is. He always finds a smile. He can be in the worst mood, but he will find a smile.

She responds when you talk to her, she sees you and smiles. She has big eyes.

She is developing a very definite desire for only me to care for her.

Other foster mothers described infants who did not give clear cues or who had behaviors that were disturbing to the foster family.

See that "Tommy", he destroys things, he's good at tearing up things.

...at three months old, she just screamed and screamed and she doesn't cuddle, she doesn't hold or cuddle.

...they (cocaine-exposed infants) don't seem to bond as much. The specialists say that babies do a lot of bonding in utero and the most we can hope for is to have attachment. But that is good enough for me.

All of the infants and foster families in this study had developed a relationship. However, foster parents had variable success at reading infant behavioral cues.

Foster Family

Five categories of foster family themes emerged: Motivation to Parent, Difficulties in Parenting, Functioning of the Nuclear Family, Needs for Support and Advice for Others.

Motivation to Parent

All families reported becoming foster parents because the foster children would not have consistent care otherwise. One mother who was the biological grandmother of her foster children put it this way:

...I took them because I didn't want any other bad things happening in their lives, they had enough....They had enough of being left alone. No one around them, not having enough food. So I wanted to make sure they had these things....I think I have put their lives together, I've made them feel like somebody cares for them.

Another mother who was also biologically related to her foster child expressed some of the same thoughts about foster parenting:

...I hate for any child to be separated, you know, from birth, to be with strangers. I think they need something consistent and it wasn't going to be with (the relative who was addicted to cocaine)...

Other families who chose to foster parent had similar reasons for doing it. One mother who had fostered many infants expressed her feelings in this way:

...I felt like I needed to do something else. Then the drug scene came upon us and it was very difficult for the (social service agency) to get kids into homes (permanent foster homes). So I thought, this is where I need to be.

The families also expressed a desire to feel needed, the belief that they could make a difference in their foster children's lives and personal reasons related to child bearing and child rearing.

One mother expressed it this way:

...My kids were in school...I don't need to have another full time job. I really wanted to do this...I think we did foster care as an opportunity to offer other women another concrete option than abortion. I think that is why I started (foster parenting).

Another mother used these words to describe her contributions:

The need was there and I love babies. And you know what?, You can only go up. If you know what you're doing with them...and I want to be on the front end. On the front end of the kid coming into the system. Because if you give them a good start, you do no harm, you do all good they can only go forward.

And another mother used different words to express a similar sentiment:

...I just love babies, I love taking care of them, I love to watch them grow.

Another family put their reasons for fostering in these colorful words:

...Oh yes, somebody need to (keep foster kids). I wish I had a bigger house where I could fit more kids. Then I could take more babies (laughter).

One mother was unable to have biological children and put it this way:

...We couldn't have kids. And I was feeling sorry for myself and I kept saying to myself, all I want to do is to take care of a baby, that's all. ...And I sat back and I heard myself and I said, well if that's the case, just take care of babies, they don't have to be your own.

Another mother who had suffered from infertility had these comments:

...After my second one (biological child),...I had a bad time with it and it never happened (having more children). I heard (a children's home) asking for foster parents. And I cried and I looked out the window and

I thought, that's what I'm going to do. The rest of my days. And I called them and it happened like that.

One foster family got very serious about fostering after the father's retirement:

...This is our humanitarian niche. He (the husband) worked for a company for 37 years and they closed his department and he said, What do we do now? And I said, we'll become professional foster parents. We always were, but now it's formal.

One foster family believed that they could give the foster child a good start in life and help them grow up better than their drug-abusing parents.

See, a kid don't have to be what they parents are, and you can always be better.

Another foster mother put it this way:

I think I have put their lives together, I've made them feel like somebody cares for them.

Families expressed a variety of motivations for fostering but two themes predominated. A belief that if you are a good enough foster parent you can help a vulnerable child overcome problems and a belief that with a drug-exposed child a foster parent can provide a better living situation than a drug abusing biological mother.

Difficulties in Parenting

Many parents experienced difficulties in parenting. Families always seemed to balance these difficulties with experiences they found more joyful. The difficulties ranged from experiencing problems with behavior to developing relationships with the infants. One mother who was well beyond the age where she would normally be parenting infants expressed these feelings:

...I like playing with them...(but) they are constantly wanting something. Even when they are in the room playing, they want something and they keep coming back to you. (Laughing) So the only free time you really have is when they are asleep....That is the thing, they are all wanting lots of attention all of the time.

Another foster mother caring for an infant who was her nephew expressed some of her thoughts this way when asked about fostering after this child leaves her:

I would really miss him a great deal. I might do this again, I enjoy working with children, I enjoy making a difference. At least I can take everything I have learned and use it.

Foster parents also expressed difficulty in parenting a baby. The older parents talked about their fatigue:

I get tired and I get sleepy and I just go on. There is no one else to take care of them. There is always something going on with them.

Younger foster parents worried about their ability to be good parents: As one younger foster mother put it:

No one ever feels prepared to meet a child's needs, because come on, it's an ongoing process. For him, as well as for you, and then sometimes, you're beating yourself over and over, asking now am I doing this for you, am I doing this for me? You have so many questions and all of them are fluttering over and over in your mind.

Older children in the household may view the foster children as a sibling and rivalry may emerge.

Now that my children are older, they're becoming kind of impatient having children with drug abuse in the house. They thought Sara was great because they didn't have to do trach changes, there were no secretions coming. But now that she's beginning to cry more and have some definite wants and needs, they don't want to be bothered with her.

Foster parenting is not without drawbacks. An additional burden may be placed on

parents and other children in the home.

Functioning of the Nuclear Family

The experience of foster parenting made a difference in the way that the family functioned. Some families found support while others discovered more negative things about their families. One mother said:

...They (rest of the family) feel that I did the right thing (fostering). But that it was the right thing for me...my Mom and my sister thought I should do it, but when I go home, they're all mine. They never give me a night off. That doesn't happen. I have a girlfriend, she will come over, she will help me wash. She helps me out real well. I have a couple of sons that help out.

Another caucasian foster mother caring for a non-white child found this response from her family:

My parents were racist and all the kids have been from non-white races. They say its ok but nobody does anything to provide any kind of support for whatever children are here. At Christmas, there are no presents...They do the bare minimum to get by. We don't get together (family gatherings).

Another mother whose husband was very involved in fostering parenting an infant expressed:

...My husband loves him so much. He's (the infant) taught me a great deal about patience and about acceptance. Because you have to have patience to do this. His learning process and all that, we have learned a lot from him. ...On the weekend, I work so he takes care of (the infant) while I work. And on a day when he is home from work at about 6 or 7, then I might go out with a girlfriend or something like that. He's real nice about it.

Needs for Support

One mother expressed her own needs for support in foster parenting her foster

daughter:

The test of my patience is what she's been. She's a pushy person, she keeps pushing and pushing. She is going to be free for adoption soon. I am considering keeping her, but I wonder what she's going to be like as a teenager. I don't know, I do ask for a lot of help with how to work with her, because she's so hard...You know, her mom had died during her birth, so she has no mom and no relative was interested in her. I don't know, she started calling me Mama and now I can't imagine her going somewhere else.

Another mother talked about her need for support and her way of obtaining relief, if not support.

...So I get out on Wednesday (when child has therapy). So once a week, I get a chance to go, you know sometimes. It is not easy. ...you get up in the morning and you get "I want a sandwich", and you tell him, you get the sandwich yourself. So I get a few minutes to myself that way.

Families also identified that other foster families had been the source of much of their support.

You know, we have a network of foster parents that you get to know and work with.

...Mostly I take her with. There are a couple of other foster mothers and we do exchange services whenever we can but it's often easier to take her with than to ask someone to take care of 3 babies.

Foster families identified their need for support but did not always find it in their biological families. Some foster families had been successful in finding support from other foster families others had not.

Advice for Others

The foster families interviewed for this study also expressed a desire to give advice to other foster families. One mother had this to say about foster parenting in

general:

...I would tell them (other families thinking about foster parenting) it is hard, it takes a lot of soul searching. My God it is hard, but it pays off.

One family felt that the literature was one-sided, and did not give the point of view of the foster family.

(Interviewer) So do you think these kids get labeled? (Mother) Yes, they just have a different start in life. I asked (told) a woman who was inservicing the teachers, you know, when you live this (with the infants) you have a different view of it.

Many of the families felt that they could not give advice but they wanted to be supportive to other foster families.

Social Systems Themes

The families also described their experience with the social systems in their lives including the family, the community, the social services system and the health care system. Few references were made to other aspects of the environment.

The Family

Several parents mentioned that they did not differentiate between foster parenting and biological parenting.

...oh, everybody just love her [speaking about the foster infant]. My daughter, my son, boy she know my son, she just smile when he comes in. We treat our foster babies just like they are members of the family. We don't have foster babies, we leave off the foster, we are parents. We try to show them the same love as if they was our own kids. We raise them like they our own kids.

Another foster mother expressed it this way:

...They are our family. We had two long term children, one for three and a half years and one for four years. They are our family.

Another foster mother was eloquent in her description of the impact of fostering on her biological children and the family :

It (fostering) has had an effect on them...the (biological) kids become very attached, so there is a lot of pain involved when they (the foster children) leave. We are finding that the older (biological) children have a very difficult time with relationships with friends...they know that the friends may leave and they (the biological children) just don't want to deal with that. So there are consequences (to foster care). We just thought it would help our children deal with loss over the years. So, they have been able to deal with losses less traumatically than other kids would because they have been exposed to finding their little tool for how to work it through. Now that my children are older, they're becoming kind of impatient having children with drug abuse in the house. They don't want to be bothered by all the care.

One mother noted that her extended family was supportive in her decision to foster parent a biologically related child but were unhelpful with actually helping to take care of him.

He's a very sweet kid and none of them would mind keeping him but then when he starts crying, everyone gets panicky and they get nervous and they run. He is back in my arms in a heartbeat.

The nuclear family of all the foster parents in this study was supportive and helpful.

The extended family was often less supportive, and in one case this lack of support had led to a massive estrangement.

At Christmas, there are no presents for the foster children, even Jose (adopted child). They do the bare minimum to get by. And that's their choice...(Interviewer) At family gatherings? (Mom) We don't get together.

The foster families had a special relationship with the extended family system. They also had a unique relationship with the community.

The Community

Most foster families reported at least some sort of community reaction to their foster parenting activity. The families were asked how they were treated in the community and how their children were received. The responses were varied and range from negative to more supportive.

One mother describes her community's reaction:

It affects the places you go because most of the kids are on apnea monitors, plus the baby. Most of our friends have older children and they don't understand why when you're 47 years old you would want to have babies in the home. We've lost some friends because the foster children are not welcome in their homes. Your life changes, but the kids are worth it.

Another foster family describes taking their foster daughter to church:

We made it an agreement when we started taking kids that every place we go the kids go. If the kids can't go, we can't go. So I tell my pastor, when I go to church, the kids are right there with me, hearing the word with me. Babies know what you are saying, and Jesus can talk more to a young mind than to an old mind.

One mother had dealt with stares and racism and had developed her own ways of living through it:

I don't care what people think, but yes, you do get stares, you do get one neighbor who made a comment, but nobody likes her anyway....My own family, they treat the kids just like their own...except my husband's mother.

Another mother had also developed her own response to fostering children in a racist community:

...adoption is out. I wouldn't even play that game (interracial adoption). It is quite hard. And I understand that cultural and heritage thing. And maybe where I live, it's not the best thing. My neighbors have not been supportive and that has been the hang up...it's a WASP neighborhood, and some of the neighbors, they don't know how to love like we do, they think we're bringing in the dregs of society. Like we're opening a halfway house. But we don't feel that way. We don't have to live with our neighbors. We've got good relatives, we don't need anything else.

A mother who was fostering four children who were racially different from her had these observations:

When I bought this house, I went around and looked at how many blacks there were because of (her foster children). We were told not to go to family outings and stuff if I was going to bring my children. But, that's fine.

The data revealed that there were racial issues when foster parents had children who were not of their race. These reactions came from the community as well as from the extended family.

The Health Care System

Foster families in this study experienced problems with access to and appropriateness of healthcare. One mother felt that she had to battle to obtain health care for her foster child.

The hardest thing to deal with any foster kids is when you enter the health care system and they don't recognize that you are the child's parent. Health care people will say stuff like, "We did such and such, you're not their parent. How would you know if you're not her mother? ...It comes from ignorance and prejudice. Especially with medically complex kids, the trachs, we have to convince people, hey it's ok, we really do know how to take care of these kids. But it's like you attach that word foster to it, people have all sorts of horror stories about it, like we're in it for the money. So, we've experienced more of a battle on that end than from the racial end. You have to be

prepared for it if you are going to foster medically needy children or drug abused children. You are going to be living in a medical world.

Another mother described her attempts to get early intervention services for a cocaine-exposed infant:

They just asked him a bunch of questions and the lady wrote everything down, but nothing is wrong with him. It's the other one that needs evaluation.

This mother felt that the health professionals were only interested in their own diagnosis, not in her observations about the foster children she was parenting.

The Social Service System

All the families had a formal relationship with some social service agency and all were licensed as foster care homes by the state. Although the quotations reported are verbatim, the specific identification of the agency is not revealed nor was any information included that would make the family readily identifiable.

All the families made comments about their social service agency. Some of the comments were positive, some constructive toward possible agency improvement and some scathing. One mother revealed that she felt that she had to participate in this interview so she could continue to keep her children (she did want to continue to participate after she was given a clear choice not to):

...once you're out (from the agency) you're on your own. You feel like if you don't do this (for example, participate in the interview). It's a threat that hangs over your head, but actually it's not. The court gives you the children, but sometimes you feel like you have to be perfect.

Another foster family had a similar experience and was given some unhelpful advice:

...(once the placement is made) they're out of there. Now I got a

caseworker, and this woman really sends me up the tree. Now I'm 63 years old and I raised I don't know how many babies, my sisters and my brothers, and I done changed diapers. She had me so confused about this baby when I got her [Referring to some healthcare issues]. The agency didn't do nothin' and they still doin' nothin'.

One mother continued to be a foster placement despite some terrible problems with foster care especially in services for children with special medical needs:

You have a lot of problems within the system that you have to deal with. You have to fight for services, you have to deal with a lot of incompetent caseworkers, you have to be harassed and intimidated by the . You don't get payment, you can't get green cards. You can't reach a caseworker...if you could just take care of the children and love them it would be okay,...but you can't do just that...If you ask a worker for it (equipment, reimbursement, etc.) they will say, we don't know what you're talking about, you can't get that. They really intimidate you and they treat you like an idiot. They don't treat you with any respect, or act like you have any intelligence. They act like you are doing this for the money. Which is ridiculous.

This mother continues to tell a story of a child who had been evaluated by a reputable physician for special education and the state agency chose to ignore that assessment.

Another mother had similar experiences with the state agency and described how she learned to deal with the foster care:

...I've always been my own best advocate and I know how to access what I need....I know how to present the material and tell them what I need them to do.... And I'm somewhat of a pioneer in what I do....So I think the system has worked well for me because I'm knowledgeable about what I have and what I need.

Families had varied responses to the payment the state makes to foster families.

One mother noted that the reimbursement actually made scheduling therapies more inconvenient for her.

(The agency) will only pay for an hour of therapy a day. So, I have to

keep going back and forth. (She has several foster children and would like to have each child have Speech, OT and PT on the same day). It's pretty tiring for me, going back and forth with these guys.

Several families mentioned a perception by others that foster families do foster care for the money. One foster mother did mention that foster care of children with special medical needs enabled her to stay at home and raise the children. Two other mothers mentioned the amount of out of pocket money they needed to contribute because the state would not adequately reimburse them for child related expenses.

I'd say 95% of the foster families have never been able to get any kind of equipment vouchers or gotten any help (from the agency)....I knew how to tap resources and I knew which papers to fill out.

Families were also lacking in other resources. These were primarily resources needed to prepare them for foster parenting cocaine-exposed infants. The foster parent agency, whether a private agency or the state agency, is currently responsible for teaching foster families about the special needs of cocaine-exposed infants. One mother received nothing.

I went for foster parents care, but nothing ever about abuse or drug babies. Nothing. I just went from love, and I took it upon my own.

Another foster mother attended training but found it unhelpful.

They told me everything I told you already that didn't apply. The kids would scream 24 hours a day, they couldn't go out in the daylight, you had to keep them in the dark room, you couldn't have any noise, you couldn't have any movement. You had to keep them wrapped up like a papoose and all you had to do was love them and love them and they would grow out of it eventually....All three of my cocaine-exposed infants were very lethargic kids, completely opposite.

Another mother with a lot of experience with cocaine-exposed infants had these

comments:

(They told us) that we should use the techniques, you know just swaddle them and use the rocking techniques. But what about your colicky baby? And most of them are...I asked about them. And they said, just let them scream. Interviewer: Foster families have been told a lot about swaddling? Yes, they have. But it's not a fix all. Sometimes it works and sometimes it doesn't. Usually it's better when the babies are a little younger. One mother told me that she had been told to swaddle the baby and it worked for the first day and then it didn't work anymore and the Mom was left with nothing because she had been told that swaddling was a cure all.

Families that had foster parented a number of children and who had a lot of experience with the foster care system seemed to have developed ways to overcome the systems shortcomings. However, if the need for foster families of cocaine-exposed infants is increasing, agencies must begin to develop a plan to adequately train more parents.

Summary

The experiences of foster families included categories of themes related to the infant, the foster family and the the social system. In the category of infant themes, two types of infant health themes were identified: physiologic and behavioral. Development and variability were also identified as infant themes. Foster family themes were: motivation to parent, difficulties in parenting, functioning of the nuclear family, needs for support and advice for others. Social system themes included: the family, the community, the health care system and the social services system. Foster family training, designed by healthcare and social service professionals, was found to be helpful to some and unhelpful or non-existent to others.

CHAPTER 5

DISCUSSION

A model of mother-infant-environment interaction created by Kathryn Barnard (1978) was selected to guide the discussion of the results of the study of the experience of foster families of cocaine-exposed infants.

The Child Health Assessment Interaction Model

Barnard's (1978) model of mother-infant-environment interaction provides a way to assess the characteristics of the mother, infant and environment and their contribution to the interaction between each of the elements.

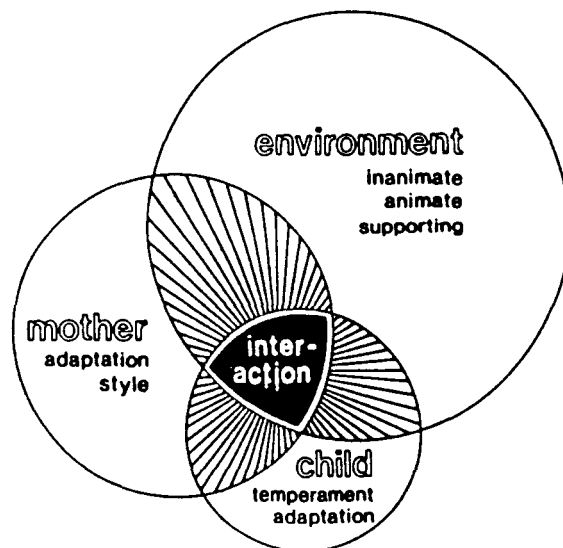


Fig.4. The Child Health Assessment Interaction Model
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p.4. Copyright 1978 by the University of Washington.

Barnard's (1978) model was selected because it is a mid-range nursing theory and has applicability in nursing practice. Barnard's model is widely accepted in nursing and other disciplines. It is frequently used as a model for infant-family research. Barnard's (1978) model also accounts for each of the broad themes that emerged in the study of the experience of foster families of cocaine-exposed infants.

The Environment

The largest circle in the model represents the environment of the child and family. The environment includes the family's community, the physical characteristics of the home and the ability of the environment to support and nourish the child and family.

The Infant

A smaller circle in Barnard's (1978) model represents the infant. Characteristics of the infant such as consolability, temperament, age and responsiveness are included in this circle.

The Mother

The mother or primary caregiver is represented by a third circle in Barnard's (1978) model. Barnard (1978) lists three tasks of the caregiver: responding to infant cues, alleviating distress and providing growth fostering situations.

Discussion of Study Results Using Barnard's (1978) Model

The Infant

Infant themes emerging from the interviews included physiological and behavioral health, development and variability across all themes. Infants cared for by foster families demonstrated a wide range of problems. Of the physiological and behavioral health themes noted in the literature, the ones most often confirmed by families were: inconsolability and feeding problems due to poor suck and lack of coordination. It is important to note that parents reported these characteristics, but qualified their reports indicating that their children had either grown out of the characteristic or were "normal". Although the literature suggests that cocaine-exposed infants are more irritable, and several parents confirmed this irritability, other parents said that their foster children were sometimes lethargic and had few sleep problems. Parents seemed to take great pride in noting that they had read that drug exposed children had certain characteristics, ie. sleep problems or constant crying, but that their child didn't demonstrate this characteristic.

Foster families who had parented many drug exposed infants over several months and years spoke about variability when describing the infants. Some infants demonstrated several behavioral indications of exposure while others had few or none.

Foster Parents Concerns Regarding Infant Health

Most of the research studies on cocaine-exposed infants note specific physical and physiological manifestations of cocaine exposure. The foster families were

frequently unaware of medical diagnoses or extent of involvement manifested in their children. One mother mentioned that one of her foster children had a grade III intracranial hemorrhage. Other mothers were able to state prematurity in terms of weeks of prenatal gestation. Several parents mentioned that their concerns were with social aspects of their child's behavior-control of anger, expression of emotions, and ability to understand concepts in school, rather than the other manifestations they had read about. One mother even stated that she felt the problems were something inside the child, waiting to explode. Medical diagnoses and physiological manifestations of exposure were not a primary concern of the families. The primary concerns were behavior and development.

Foster families reported variability among infants. Families who had parented many cocaine-exposed infants noted that some infants had many behavioral manifestations of exposure while others had few or none. Foster parents even found variability within individual infants. They described infants who were cheerful, alert and responsive some of the time and were absolutely unpredictable and inconsolable at other times.

Parents frequently reported other behaviors that concerned them or that weren't picked up through standardized testing. They did not want their infants to be identified only by the label "coke baby" and singled out for special programs. However, they did want the children to be tested, and if appropriate, allowed access to intervention. Parents were more concerned with behavioral health than physiological manifestations of exposure. They felt their observations about these

infant behaviors were often overlooked by health care professionals.

Health-care practitioners have rushed to implement intervention programs for these infants before documenting the short and long term effects of exposure. While these interventions are not harmful, they are quite costly because of the intensity of professional contact required. Almost no work has been done to determine which interventions are ultimately helpful or unhelpful.

Caregiver-Infant Interaction

Barnard's model (1978), as shown by the intersection of the circles, provides a way to examine caregiver-infant interaction. The interaction was observed during interviews and recorded through field notes.

Barnard's (1978) theory suggests that infants exert an influence on their caregivers. This investigation of foster families of cocaine-exposed infants confirmed that these infants exerted a powerful influence on their caregivers. Several foster mothers told the investigator about their desire to adopt their foster infants. Four of the foster families had already adopted drug-exposed children they had foster parented in the past.

The emotional ties between foster families and their foster infants were strong. Families sometimes chose to continue foster parenting cocaine-exposed infants despite the lack of support from extended family and the social service agencies.

The interaction between the foster family and the foster child was so powerful that parents minimized outward evidence of cocaine-exposure. Physical evidence of exposure such as erratic behavior, inconsolable crying, high pitched screaming, poor

eye contact, behaviors evident to the investigator during the interviews, were not reported when foster parents described their foster infants. Foster mothers, in particular, redefined the behavior of the foster infants. They described their infants as "just like other babies". Parents who fostered many different infants saw each infant as an individual. The interaction between family and infant was determined by the unique characteristics of the child, the child's temperament and adaptability to the foster parents.

It has been postulated that cocaine exposure in an infant leads to compromised caregiver-infant interaction because of the neuro-behavioral disorganization of the infant (Sweeney, 1989). Sweeney (1989) suggests that cocaine-exposed infants who exhibit poor state control are at risk for child abuse. Foster families in this study found many ways to minimize neuro-behavioral disorganization in the cocaine-exposed infants and were able to develop interactional relationships with their infants.

Studies in progress at this time suggest that drug-exposed children may experience developmental delays into childhood and that the neurologic abnormalities seen in cocaine-exposed children may lead to language, adaptive behavior, fine motor and cognitive skill delays (Azuma & Chasnoff, 1993, Dixon, 1989, US-GAO/HRD-90-138, 1990). This study found that foster families are in a good position to observe these behaviors in a real-life setting.

The Foster Family

This study demonstrated that there is no one set of experiences that defines the experience of all foster families of cocaine-exposed infants. However, there were

some themes common among all the families interviewed that will help nurses understand and plan appropriate interventions with foster families. These themes included: the motivation to parent, difficulties in foster parenting, functioning of the nuclear family, needs for support and advice for other foster families.

Every single family interviewed, in some way, felt that they were doing something good for children by becoming foster parents. Some parents were quite descriptive in what they were doing, "giving them a good start", while others felt that they were protecting the children from a very bad family situation or from being raised by strangers. A few families mentioned that foster parenting was their "job", role, or even "mission" in life. A few of the parents who had fostered children not biologically related to them told accounts of infertility or the desire to have more children, but not biological children. All the parents felt that they were giving something back to society or to the community by being foster parents.

Families concentrated their emotions on the relationship with the foster child. They did not express anger toward the child's biological mother. Foster parents redirected anger toward the social services system. The two families who were legal foster parents to children who were biologically related to them restrained their anger toward the child's biological mother. Most parents also mentioned that, just because a baby was born from a mother with a (drug) problem, people shouldn't judge that the baby had a problem. The child was accepted for their abilities and unique qualities regardless of the parents drug abuse.

Families often found support from within their nuclear family or from other

foster families. Along with the difficulties families encountered, they experienced a need for respite and relief from the responsibility. Mothers were usually more involved with the day to day parenting than fathers. The husband was involved in the decision to foster. Foster fathers were sometimes more involved in setting limits on the nurturing behaviors of the mothers than in day to day care of the foster infant. For example, one foster mother wanted to devote her life to becoming a home or shelter for foster children. Her husband was not supportive of the idea. Another mother had decided to do short term emergency care after a bad experience with an infant and the foster care agency but was hoping a long term placement would come along. She described how she planned to get one foster baby into her home before her husband realized what had happened.

Families were questioned about advice they might offer other foster families. Most foster parents were reluctant to offer advice beyond sharing what they had gained from fostering and admonishing other foster parents to be aware of the many difficulties.

Barnard's (1978) model (Figure 4) includes a circle representing the characteristics of the caregiver. In this study, there were many different caregiver characteristics, all significant in the foster family experience. Some of the caregivers had adequate economic support, some did not. Some of the caregivers were young and relatively energetic, some had already raised many children and were now raising foster children. This study did not try to determine the exact influence of each of these characteristics either singly or in combination on the foster family experience.

The Environment

The largest circle in Barnard's (1978) model (Figure 4) represents the environment. The results of this study were organized using the term Social System to include the extended family, the community, the health care system and the social services system. Barnard (1978) includes each of these systems in the animate and inanimate components of the environment.

The Extended Family

This study suggests that that foster parents may experience special reactions from the extended family. The study found that the extended family may react to racial differences between the biological family and the foster child. The study also found that the extended family may treat foster children differently than they treat children biologically related to themselves. In every case in this study, some biologically related family members were seen as outsiders by the foster parents. Foster families with the least support from their nuclear and extended families reported the most difficulty in day to day foster parenting. Family members who supported each other, especially those with support from family members outside the household found foster parenting more personally fulfilling.

It should be noted that the extended family did not appear to have interactions with the social services system unless members of the extended family were living in the foster family's home.

The Community Environment

The community environment is important to the foster family. Several foster

families noted that their communities were racist. Neighbors and strangers in the community reacted negatively to foster parents who cared for racially different foster children. Most foster families overlooked this ostracism by relating to other foster families. But, most felt that they were different from other members of their community. At least one foster family had chosen to live in a particular development in a community because the people were supportive. It is imperative that this issue be recognized, as more and more children are placed in racially different foster homes. Although exact statistics are not available, there will be a greater need for foster homes for African-American children than there are African-American foster homes available (Soliday, McCluskey-Fawcett & Meck, 1994).

Health Care System

The social service system is also responsible for providing access to medical care for foster children. One study (Cain & Barth, 1990) confirmed the inadequacy of medical care for foster children. Foster parents in this study identified that they had trouble receiving appropriate reimbursement for medical care. They also indicated concerns with the way they were treated by the health care system. They felt their experience in caring for the infants was discounted because they were foster parents not biological parents or adoptive parents. Others felt that the medical system and the social service system failed to recognize their concerns about the need for developmental screening based on the foster parents' observations of the infants in the home environment. The findings of this study were confirmed by a study of pediatricians and foster care providers by Simms & Kelly (1991) indicating that foster

children often receive inadequate care due to lack of communication between foster parents and healthcare providers.

The Social Services System

The foster families were a rich source of data about the relationship of social service agencies and foster families. Agencies can develop specific recruitment and support mechanisms for foster families if they have information on the effectiveness of their current programs and interventions. One family reported that they had received no training on how to care for cocaine-exposed infants. Other families found the training they did receive was not helpful. One foster mother felt that the agency made her comply with certain interventions that were not only unhelpful but hindered her parenting (apnea monitoring).

The popular press and electronic media carry daily reports of social service agency failures. These range from failure to recognize abuse to almost incomprehensible incompetence. The foster families in this study confirmed these reports. Individuals working with a private agency generally reported more personal contact with their social worker. Families who had chosen to become professional advocates for foster families were usually satisfied with their role in getting social services from the agency. However, every family reported some problems with the agencies. These problems ranged from needs for equipment and health care payments to caseworkers giving misinformation about the children being placed. One parent expressed the worry that she might be placing her family at risk for HIV because the agency refused to tell her if the child she was fostering was HIV positive. Agency

policy does not require that foster families be told of HIV status in infants because many infants who are born HIV positive generally become negative by age 18 months. Another mother said that the agency had given her so much misinformation about the background of the children that she was afraid she might have to relinquish them. Foster families are licensed by the agency. They are required to be in contact with the agency. One is led to ask, Why do the agencies not listen to foster family concerns?

Foster families receive little support from the social service agencies that place the children. Families reported equipment, monetary and medical service needs that were inadequately met by the social service agency. One study by Chamberlain, Moreland & Reid (1992) confirmed the inadequacy of services and reimbursement for foster families and suggested areas for improvements. Two of the foster mothers in this study had become professional advocates for other foster families. Despite their knowledge of the system and how to access it, they continued to be concerned about the treatment they and other foster families receive from agencies. The stories of the lack of services from the agency represent an area for systematic investigation in future studies.

Areas for Future Research

The Barnard model (1978) proposes that interventions be based on building contingent relationships between the infant and caregiver. Tools such as the Nursing Child Assessment Feeding Scale (NCAFS: Feeding Scale), teaching (NCATS: Teaching Scale) and sleep activity (Sleep Behavior Record) have been tested with

many infants including those in foster care. Studies of cocaine-exposed neonates suggest that a drug exposed infant could demonstrate compromised function in each of these areas. However information to support the duration of the compromise is not available. These aspects of behavior were selected because they represent those frequently occurring in normal caregiver-child interactions. Assessment of the infant's physical appearance, temperament and the child's ability to adapt to his/her caregiver and environment is also suggested. Investigations to confirm the duration of consequences of cocaine exposure are a priority concern. The variability of effects of cocaine exposure indicate a need to view exposure on a continuum from no manifestations to many manifestations of exposure. Future investigations could be strengthened with multiple measures at critical developmental periods.

Further research is also recommended on the impact of foster parenting on the family. This study found that the extended family exerted a strong influence on the foster family. This is an area for future studies. Several of the foster mothers spoke of loss when talking about foster parenting. Further research could examine the relationship between foster parent and child when the child is not adopted.

Other families spoke of the influence of the foster infant on their nuclear family, spouse relationships, siblings and other relationships with biologically related family members. The impact of foster parenting on these relationships needs to be examined.

Research should also continue to address issues involving social service agencies and foster families. This is an area of grave concern to those who are foster

parenting.

Without further research, agencies may continue to develop ineffective training programs. Agencies also need information on how they can effectively channel their limited dollars to appropriate therapies and equipment.

Limitations

There are several limitations to this study. This study did not examine infant behaviors except by foster parent report. While this method allowed an investigation of behaviors most relevant to caregivers, the findings cannot be generalized to the population of cocaine-exposed infants. Future investigations should include both parent and investigator measures of behavior.

Although every attempt was made to interview the members of the household involved in parenting the foster child, the results are primarily from a foster mother's perspective. In the future an attempt should be made to interview other family members.

Because this study focused on the perspective of the foster family, no attempts were made to include the perspectives of the extended family, social service agencies, communities or health care providers. The site of this research was urban Illinois. Other states may have a different social service system. The perspective of rural foster families may also be different from urban. Those from culturally different groups than the ones studied (African-American and Caucasian) may also yield different results. Further research with more families may allow for more understanding of the effects of community values and cultural composition.

Significance of the Study

This study found variability in the experience of foster families parenting cocaine-exposed infants. Each infant and family member brought unique qualities to the interaction. Because this study was conducted in a naturalistic setting, themes emerged as the foster families had experienced them. The foster infants had variable expressions of cocaine-exposure. Because much of the previous research has been done in controlled environments during the first months of life, long term behavioral manifestations of prenatal cocaine-exposure have received little attention. Parents reported that the infants they fostered demonstrated many of the symptoms thought to be typical of cocaine-exposure. Foster parent report and investigator observations found: poor feeding, poor muscle tone, tremors, crying and other behaviors indicative of neurological insult. However, some infants did not demonstrate these effects. Parents generally found that the effects were diminished the longer the child was in the home with the foster parents. This does not mean that foster families found these infants to be without damage from the exposure. Families observed social and interactional behaviors in the infants that led them to believe the long term effects of the exposure continue in a different way. This study affirmed that foster families worry about the future of the children they foster. They feel that the social service system that does not meet their needs. They worry about aspects of the cocaine-exposed infant's development and behavior that may emerge in the future as the child begins school and a social life outside the foster family. Foster families are concerned about the support they receive, from their community, their extended families, the

health care system and the social service system. This study has also shown that families are concerned about the biological parents of the infants and feel that the foster family environment may be preferable for nurturing the vulnerable child versus the drug-abusing environment of the biological parents.

Implications for Practice

Foster families mentioned that their preparation to parent cocaine-exposed infants was often not based on their individual child and was irrelevant to needs of the child beyond the early infant days. Parents were told to use interventions such as apnea monitors that actually hindered care for the child. The need for this intervention for all cocaine-exposed infants has never been documented in the literature. Parents need information in areas where nursing can make a significant contribution, such as feeding infants and skin care. It is appalling that existing knowledge related to these areas has not been systematically integrated into the training parents receive.

There is also a need for nursing and other health care providers to understand the impact foster families have on the children they parent. In only one example did a foster mother mention the helpfulness of a health care provider. One family who received care from a community based nurse practitioner was satisfied with the health care they were receiving. Others, receiving care from tertiary medical centers, found that their concerns about the foster infants were not heard. Foster parents are sometimes seen by health professionals as having no knowledge about the child yet the foster parents in this study devoted their entire lives to parenting the children.

Nursing and other disciplines need to listen to the foster parent and include this information into the development of the plan of care. Plans of care for the most troublesome aspects of parenting cocaine-exposed children such as feeding, expression of emotions, behavior and skin care need to be developed and tested. Nurses must also help other health care providers understand that coordination of services (medical, PT, OT and Speech) is crucial for families trying to parent foster children with special needs.

Policy Development

Cocaine-exposed infants and the foster families who care for them present our society with tremendous challenges. The research on cocaine-exposed infants has not yet provided a basis for programs of universally appropriate specific intervention programs. Some problems are identifiable and require planned intervention. Early intervention programs should be available to all cocaine-exposed infants. One mother said it succinctly, "Early intervention programs really work, especially mom and tot. I think it is important to identify, not to label". Policy makers need to listen to these foster parents, to their real life experience with cocaine exposure. As the same mother put it, "you know, when you live this (parent a cocaine exposed child) you have a different view of it". Programs must be available first, to prevent the exposure during and prior to pregnancy, and second for the infants, to determine the effects of exposure and to plan early intervention to minimize the effects. These children can be placed in early intervention programs currently available and individualized treatments designed based on the manifestation of exposure. There is no reason to label these

children just because of exposure, but neither is there a reason not to intervene.

These children are at risk.

The social system and the health care system should institute sweeping policy changes to appropriately care for these children and to support the foster families who participate in their care. This study indicates that foster families have overwhelming problems with agencies regarding services, equipment and communication. As one mother put it about the agency and the caseworkers, "I think they believe they can walk on water. Yes, that's what they believe. They think they are God. They are on power trips." This was not the experience of all foster families studied but this mother was graphic in her description of an agency that actually did harm to a child.

The health care system has not adequately addressed the needs of cocaine exposed children. While studies cited in this work have been used to dramatize the physical and physiological effects of exposure, little attention has been paid to the social aspects of this problem. Interviews with families in this study, as well as in other studies suggests that cocaine-exposed infants have a higher incidence of respiratory illnesses, otitis media, feeding problems and skin problems. There has been little documentation of this and parents have a great deal of difficulty in getting appropriate health care for these children. Foster parents waiting for a medical card (provided by the agency) may find themselves making out of pocket expenditures for doctor visits and medications. Policies need to be changed to allow foster parents to access to the health care system.

Summary

Prenatal cocaine exposure has had a significant impact on health care and social services systems. The demand for foster care for infants has increased 25-29% since 1985 primarily due to drug exposure. Many have suggested that there is an increased incidence of physical neglect and maltreatment (US-GAO-HRD-90-138, 1990). While researchers are still investigating the long term effects of prenatal cocaine exposure, many have suggested the children may have potential learning disabilities, and under achievement leading to increased illiteracy and future unemployment due to the effects of cocaine exposure on the developing brain.

The experience of foster families of cocaine-exposed infants sheds new light on understanding the needs of exposed infants as they grow and develop. While a great deal of attention has been paid to understanding the effects of cocaine exposure prenatally, few studies have looked at the children longitudinally. Only one published study has dealt with cocaine-exposed infants in a home environment. The study reported here has added to knowledge about cocaine-exposed infants in the foster family setting. We now have evidence that foster families are often very committed to parenting these children against formidable limitations in support from extended families, the community, and most significantly the social services system. This study also demonstrated that foster families are observing behaviors, possibly due to cocaine exposure, that have them worried about the future development of the children. While schoolteachers and others express concerns about learning disorders in these children, foster families are worried about expression of emotion, and labile behavior.

Foster families are able to observe these children as they grow and develop, but find that their observations are not considered by health care professionals and the social services system. This study has shown that foster families, especially those who have fostered a large number of cocaine-exposed children, are in a position to offer significant data about these children as they grow. The research with cocaine-exposed children and their foster families must continue. There is a need for longitudinal research designs, observation of the children in a natural environment, and a focus on interaction between the child and others in the environment.

APPENDIX 1
SUMMARY OF THE LITERATURE ON THE EFFECTS OF COCAINE-
EXPOSURE IN INFANTS

STUDY	SAMPLE	PURPOSE	FINDINGS
Anday, Cohen, Kelley & Leitner, 1989	19 cocaine exposed infants matched with 19 drug free infants.	To examine the effect of prenatal cocaine on acoustic sensorineural reactivity.	Infants exposed to cocaine experience larger glabellar reflex and are more reactive in general suggesting an effect on sensorineural processing and increased risk for cognitive and/or neurological sequelae.
Bateman & Heagarty, 1989	4 children exposed to freebased cocaine (crack).	These case studies described effects of passively acquired cocaine in 4 children whose adult caretakers were freebasing cocaine.	2 children had transient neurological symptoms (drowsiness and unsteady gait), 2 experienced seizures.

STUDY	SAMPLE	PURPOSE	FINDINGS
Bauchner, Zuckerman, McClain, Frank, Fried & Kayne, 1988	996 pregnant women, 175 used cocaine during pregnancy.	This study examined the risk of SIDS in cocaine-exposed vs. non-exposed infants.	Risk of SIDS in cocaine-exposed was 5.6 per 1000 vs. Risk of 4.9 per 1000 in non-exposed. Study suggests no increased risk of SIDS in exposed infants.
Bingol, Fuchs, Diaz, Stone & Gromisch, 1987	3 groups consisting of 50 women with cocaine use, 110 women with polydrug use and 340 women who were non users. All groups similar for S-E status, cigarette smoking and ethnicity.	This study examined the teratogenicity of cocaine.	Stillbirth higher in cocaine using mothers ($p < .01$) All stillbirths were related to abruptio placenta. Birthweight, length and head circumference lower in drug using groups ($p < .0001$) No differences among the drug using groups on the above characteristics.
Burchfield, Graham, Abrams & Gerhardt, 1990	Animal study using pregnant sheep and their fetuses	To determine the effect of direct administration of cocaine on fetal behavioral state in sheep.	Rapid eye movement during sleep was affected by cocaine administration, mean arterial pressure was also increased. Authors suggest that cocaine directly alters behavioral state which may play a role in abnormal behavior in cocaine-exposed newborns.

STUDY	SAMPLE	PURPOSE	FINDINGS
Burkett, Yasin & Palow, 1990	139 cocaine using mothers and their infants.	To examine the prevalence of poor perinatal outcomes in a cocaine exposed population.	Consistently increased low birth weight, SGA, precipitate labor, meconium staining, lack of prenatal care neurologic problems and syphilis in cocaine-exposed infants.
Burns, Chethik, Burns & Clark, 1991	5 cocaine using mothers.	To use a newly designed instrument (PCERA) to quantify mother-infant interaction.	Compared to norm, drug abusing mothers showed an increased tendency toward rigidity and overcontrol in parenting, lack of enjoyment and pleasure toward infants and limited emotional involvement and responsivity in interaction.

STUDY	SAMPLE	PURPOSE	FINDINGS
Chasnoff, Burns, Schnoll & Burns, 1987	23 cocaine using mothers, divided into two groups: cocaine-using only and cocaine plus narcotics. These two groups compared with a group of women maintained on methadone alone and one drug-free group.	This study examined perinatal and neonatal effects of cocaine use during pregnancy.	Women using cocaine had a significantly ($p < .05$) higher rate of spontaneous abortion. Neonatal gestational age, birth weight length and head circumference were not affected by cocaine exposure. Infants exposed to cocaine demonstrated significant depression of interactive behavior and poor state organization on the NBAS.
Chasnoff, Burns, & Burns, 1987	52 cocaine using women compared with 73 women using methadone during pregnancy.	This study compared perinatal and neonatal outcomes between cocaine using and methadone using women.	Findings indicate a higher incidence ($p < .05$) of premature labor, precipitous labor, abruptio placenta, fetal monitor abnormality and fetal meconium staining in cocaine exposed infants. No significant differences were found between groups in birth weight, length or head circumference.

STUDY	SAMPLE	PURPOSE	FINDINGS
Chasnoff, Bussey, Savich, & Stack, 1986	32 women with known cocaine use.	This study examined the incidence of infant cerebral infarction in cocaine-exposed infants.	An increased incidence of cerebral infarction ($p < .05$) was found in cocaine-exposed infants vs. a non-exposed population.
Chasnoff, Chisum & Kaplan, 1988	23 cocaine using women divided into cocaine only and polydrug using groups.	This study examined genitourinary tract malformations in infants exposed to cocaine in utero.	An increased incidence of genitourinary malformations (hypospadias, prune-belly, ureteral displacement) was found in cocaine exposed vs. poly drug exposed infants.

STUDY	SAMPLE	PURPOSE	FINDINGS
<p>Chasnoff, Griffith, MacGregor, Dirkes & Burns, 1989</p>	<p>75 cocaine abusing women divided into 2 groups. One used cocaine only during 1st trimester (n=23), one group used cocaine throughout pregnancy (n=40). Groups matched with a group of women who had no history of cocaine use (n=40).</p>	<p>This study described perinatal outcomes between 1st trimester cocaine users, those who used cocaine throughout pregnancy and those who did not use cocaine.</p>	<p>Women using cocaine throughout pregnancy experienced increased preterm delivery, LBW infants (low birth-weight) and IUGR (intra-uterine growth retard-ation). Women using cocaine only during the 1st trimester experienced these complications at a rate similar to the non-exposed mothers. Mean birth weight, length and head circumference were reduced in women who used cocaine throughout pregnancy. Cocaine exposed infants in both groups demonstrated significant impairment of orientation, motor and state regulation behavior on the BNBAS (Brazelton).</p>

STUDY	SAMPLE	PURPOSE	FINDINGS
Chasnoff, Hunt, Kletter, Kaplan, 1989	32 cocaine exposed and 18 methadone exposed infants matched for maternal age, race, cigarette, ETOH, and marijuana use and in gestational age, sex.	Examined the respiratory system effects of drug exposure.	Incidence of SIDS in cocaine exposed group was 15% in methadone group 4%. Respiratory pattern abnormalities showed an increased risk of apnea of infancy, and cardio-respiratory abnormalities in cocaine exposed infants.
Chasnoff, Lewis & Squires, 1987	1 case study.	This study described the effects of cocaine exposure in a breast fed infant.	A baby was found to have temporary neurological effects of cocaine acquired through her mother's breast milk.
Chavez, Mulinare & Cordero, 1989	791 babies with urogenital anomalies were matched with 2973 infants with no anomalies. Retrospective review determined cocaine exposure.	To examine the incidence of urogenital anomalies in cocaine-exposed infants.	Increased urological system defects ($p < .05$) in cocaine-exposed infants. No significant difference found between groups on genital organ defects.

STUDY	SAMPLE	PURPOSE	FINDINGS
Cherukuri, Minkoff, Feldman, Parekh & Glass, 1988	55 women using crack during pregnancy, matched with 55 non drug using mothers.	This study examined perinatal and neonatal outcomes of alkaloidal cocaine (crack) exposure.	Women using crack more likely to deliver prior to term ($p < .001$) Crack exposed infants more likely to experience IUGR ($p < .006$), and greater incidence of head circumference below the 10th percentile ($p < .007$). No significant neuro behavioral symptom differences were found.
Chiu, Vaughn & Carzoli, 1990	207 infants born after cocaine exposure.	Examination of prevalence, demographics and hospital length of stay and cost associated with cocaine exposure.	45% of total length of stay for cocaine-exposed infants was due to "social hold" to determine home placement for the child. Total hospital charges were 100% higher for cocaine-exposed vs. non-exposed population.
Chouteau, Mamerow & Leppert, 1988	343 women with cocaine positive urine toxicology studied retrospectively.	This study examined the effects of third trimester cocaine exposure on perinatal outcomes.	Multiple regression revealed that low birth weight and early gestational age were significantly correlated with cocaine exposure. No correlation was found between cocaine and abruptio placenta or maternal hypertension.

STUDY	SAMPLE	PURPOSE	FINDINGS
Church & Overbeck, 1990	Animal study using dose controlled cocaine in rats.	Examination of dose related effects of cocaine on brainstem auditory evoked response test in rats.	Abnormal BAER was found only in rats exposed to high doses of cocaine and only at 35 days after birth suggesting that effects of cocaine in infants are dose related and may dissipate over time.
Collins, Hardwick & Jeffrey, 1989	1 Case study.	Perinatal complications in a cocaine abusing mother.	Abruptio placenta, preterm labor and rapid delivery occurred in the mother. Neonate developed RDS with persistent pulmonary hyper-tension and signs of neurologic dysfunction.
Cordero & Custard, 1990	69 cocaine exposed infants with mothers enrolled in a high risk perinatal project compared with 66 infants not enrolled.	To compare outcomes between those enrolled in the project and those who received "walk-in" services only.	Prematurity rate was decreased for those infants in high-risk project. SIDS, AIDS and DD were similar in both groups.
Czyrko, C. Del Pin, C., O'Neill, J., Peckham, G., Ross, A., 1991	11 cocaine exposed infants with NEC matched with 51 babies born with NEC but without cocaine exposure.	To examine differences in NEC course between cocaine-exposed and non-cocaine exposed infants.	Infants with cocaine exposure experienced significantly more surgical intervention, massive gangrene, and increased mortality.

STUDY	SAMPLE	PURPOSE	FINDINGS
Dixon & Bejar, 1989	74 infants with poly drug exposure including cocaine matched with 87 infants with similar hypoxeschemic encephalopathy.	To examine cranial abnormalities in infants exposed to cocaine and other drugs.	Drug exposed infants experienced IVH, echodensities associated with necrosis and cavitory lesions, focused in the basal ganglia, frontal lobes and posterior fossa. Authors argue for significant risk in drug exposed infants for experience of cerebral injury.
Dixon, 1989	13 cocaine using mothers, 28 methamphetamine using mothers and 45 mothers with no drug use were compared.	To examine neonatal outcomes of cocaine and methamphetamine exposure.	All infants with drug exposure were found to have increased preterm delivery, lower birth weights, increased anemia, and smaller head circumference. BNBAS demonstrated profound alteration in visual processing quality of alertness, tremulousness and startle reflex in exposed infants. Almost all cocaine exposed infants showed abnormal visual evoked potentials. Cases reported of spastic quadriplegia, hemiplegia, microcephaly, global delay and seizures.

STUDY	SAMPLE	PURPOSE	FINDINGS
Dominguez, Vila-Coro, Slopis, & Bohan, 1991	10 case studies of infants with DD and cerebral anomalies found to have vasoactive drug-exposure.	Description of ophthalmological abnormalities in these infants.	9 infants with ophthalmological problems; strabismus, nystagmus, and/or hypoplastic optic discs.
Frank, Bauchner, Parker, Huber, Kyei-Aboagye, Cabral & Zuckerman, 1990	1092 infants examined for presence of metabolites of cocaine and marijuana postnatally.	To discover intrauterine growth abnormalities associated with either cocaine or marijuana.	Decreased birth weight for both drug exposed groups. Suggestion that marijuana may retard growth through maternal-fetal hypoxia, while cocaine retards growth through alteration in nutrient transfer to the fetus and fetal metabolism.
Fulroth, Phillips & Durand, 1989	86 infants born to women with known cocaine and or heroin use.	To describe perinatal outcomes of infants exposed to heroin and or cocaine in utero.	Increased incidence of preterm births, increased microcephaly and SGA in cocaine exposed infants. Microcephaly also significant in the cocaine/heroin group.

STUDY	SAMPLE	PURPOSE	FINDINGS
Gingras, O'Donnell & Hume, 1990	Study of literature related to pathophysiology of cocaine exposure.	Examination of abnormalities of CNS associated with cocaine exposure synthesized with mechanisms known to be associated with SIDS.	Cocaine alters metabolism of norepinephrine which may alter infant arousal making infants more likely to experience SIDS.
Gingras & Weese-Mayer, 1990	Examination of the literature proposing an animal study of neurotransmitters affected by cocaine exposure.	To propose an animal study examining rabbit fetal brain development with cocaine exposure.	Researchers hypothesize that cocaine use alters normal maturation of brain centers and/or neurotransmitters involved in respiratory control causing an increased risk in infants for state dysfunction and possible SIDS.
Greenfield, Rutigliano, Steinhardt & Elder, 1991	4 case studies of cocaine exposed infants with urologic anomalies.	To determine the type of urogenital abnormalities in cocaine exposed infants.	Male infants predominate. Authors conclude that cocaine disrupts morphogenesis by vasoconstriction of uterine and fetal circulation.

STUDY	SAMPLE	PURPOSE	FINDINGS
Habel, Kaye & Lee, 1990	1000 live births examined for drug exposure.	To determine the incidence of drug exposure in the sample and to examine sequelae of drug exposure in the population.	Increased incidence of drug exposure from 1981 - 1987 due primarily to cocaine. Opiates and cocaine associated with increased mortality and low birthweight. Death rates increased for SIDS and AIDS in the drug exposed population.
Henderson & McMillen, 1990	Animal study of cocaine-exposed vs. non exposed rats.	To determine differences between exposed vs. non exposed rats on birthweight, anomalies, state related behaviors related to cocaine dosage.	Cocaine exposed rats were more hyperactive at 30 days of age, had decreased birthweight with increased effects at higher dosages of cocaine. Study suggests that there are dose related effects on outcome and long term development.
Hadeed & Siegel, 1989	56 cases of cocaine exposed infants matched with non drug exposed controls.	To study the effects of cocaine exposure on the newborn.	Increased microcephaly in cocaine exposed infants ($p < .01$) increased IUGR, no increase in teratogenicity.

STUDY	SAMPLE	PURPOSE	FINDINGS
Hickson, Altemeier, Martin & Campbell, 1989	9 Case Studies.	To describe life-threatening poisonings by caretakers.	Infants with no known drug screen presented with poisonings by caretakers primarily mother. Poison used included cocaine presumably to quiet a fussy infant.
Hoskins, I., Friedman, D. Frieden, F., Ordorica, S., Young, B, 1991	314 pregnant women having serial umbilical artery Doppler.	Correlational study between incidence of abnormal serial doppler and cocaine exposure, placental abruption and preterm labor.	Cocaine exposed infants with abnormal serial dopplers had significantly more preterm labor and abruptio placenta.
Hoyme et al, 1990	Case study of 10 cocaine exposed infants.	Description of vascular disruption in cocaine-exposed infants.	9 of 10 infants studied had congenital limb reduction defects or intestinal atresia or infarction.
Hume, et al, 1989	20 cocaine exposed infants.	Comparison of fetal and newborn behavioral state in cocaine-exposed fetuses and newborns.	Abnormal fetal state was predictive of newborn state disorganization ($p < .05$) Fetal state disorganized was predictive of newborn state disorganization ($p < .01$).

STUDY	SAMPLE	PURPOSE	FINDINGS
Lipshultz, Frassica, & Orav, 1991	214 cocaine-exposed infants compared to 340 non-exposed infants. These infants matched with a cardiology referral database.	Study to determine the incidence of cardiovascular anomalies in cocaine-exposed population.	Significantly more cardiovascular anomalies in cocaine-exposed infants ($p < .05$). Suggestive of cocaine-exposed infants more likely to have structural CV malformations, ECG abnormalities and CV autonomic dysfunction.
Little, Snell, Klein & Gilstrap, 1989	53 cocaine abusing mothers compared with 100 mothers without drugs.	Study compared fetal outcomes and perinatal complications in cocaine exposed vs. non exposed mothers and infants.	More pre term labor ($p < .05$) in drug exposed infants, More meconium staining, tachycardia, low birth weight, cardiac anomalies (A-V malformations VSD), cardiomegaly ($p < .01$) in cocaine exposed infants.
Little & Snell, 1991	80 cocaine exposed infants, matched with 100 non drug exposed infants, and 67 infants exposed to alcohol alone.	To compare differences in brain growth between drug exposed and non exposed infants, and differences in brain growth between cocaine exposed and alcohol exposed infants.	Alcohol and cocaine exposed infants not significantly different from each other in head circ. Significant differences in brain growth between both cocaine and alcohol exposed infants compared to control ($p < .001$)

STUDY	SAMPLE	PURPOSE	FINDINGS
Mastrogiannis, Decavalas, Verma & Tejani, 1990	88 infants born with cocaine exposure. 44 had recent exposure, 46 were exposed earlier in the mother's pregnancy.	Description of differences between recent and chronic cocaine exposure.	Preterm labor, premature rupture of membranes and meconium staining were more prevalent in recently exposed neonates. Low birth weight growth retardation and abruptio placentae were more frequent than in the non-exposed population but there were no differences in these occurrences between recently exposed infants and those with exposure earlier in the mother's pregnancy.
McCalla, Minkoff, et al, 1991	846 mothers of whom 11.5% drug positive for cocaine in urine.	To describe the frequency and consequences of prenatal cocaine use.	Cocaine exposed infants had lower birth wt. ($p < .001$), increased probability of Apgars < 7 (.0001)
MacGregor, et al, 1987	70 women with cocaine exposure compared with 70 non drug exposed women.	Describe the perinatal outcomes of drug exposed infants.	Cocaine exposed infants experienced lower gestational age at birth, increased risk for preterm labor, LBW and SGA.

STUDY	SAMPLE	PURPOSE	FINDINGS
Nanda, Feldman, Delke, Chintaltapally, & Minkoff, 1990	86 drug exposed infants, of these 87.9% were cocaine-exposed.	Describe the use of prenatal care by drug using pregnant women and incidence of untreated syphilis in drug using population.	75.8% of women using drugs during pregnancy reported no prenatal care significantly ($p < .001$) different from non drug using mothers. Several mothers has untreated syphilis and infants born with congenital syphilis.
Neerhof, MacGregor, Retzky & Sullivan, 1989	1776 mothers and their infants.	Describe the prevalence of cocaine exposed births and associated perinatal outcomes.	8% of births were exposed to cocaine in the 3rd trimester. These showed increased neonatal morbidity, longer hospital-izations ($p < .05$), increased incidence of lower gestational age at delivery, prematurity and premature rupture of membranes ($p < .05$).
Neuspiel, Hamel, Hochberg, Greene & Campbell, 1991	51 cocaine exposed infants matched with 60 non exposed infants.	To examine differences in infant behavior and maternal-infant interaction in drug-exposed vs. non exposed infants.	No differences in NCAFS or NBAS exam (when confounding variables were controlled) between groups.

STUDY	SAMPLE	PURPOSE	FINDINGS
Oro & Dixon, 1987	104 cocaine exposed infants with 3rd trimester exposure to cocaine or methamphetamine or both.	Description of cocaine withdrawal symptoms in infants.	All groups had altered behavioral patterns with respect to abnormal sleep patterns, poor feeding, tremors and hypertonia. Multiple regression demonstrated that cocaine or methamphetamine exposure was associated with decreased gestational age, birth weight, length and head circumference.
Parker, Zuckerman, Bauchner, Frank, Vinci, & Cabral, 1990	936 full term infants examined for jitteriness.	To determine presence of jitteriness in infants exposed to marijuana and cocaine.	Jitteriness observed more often in infants exposed to marijuana than cocaine, magnitude of effects of either drug on jitteriness was small.
Porat, R., & Brodsky, N., 1991	Study of four relatively large infants with cocaine exposure and NEC.	To examine the course of NEC for cocaine exposed infants compared to usual risk factors for NEC.	Feeding intolerance should signal suspicion of NEC in term and near term infants who are cocaine exposed due to reduced GI blood flow.

STUDY	SAMPLE	PURPOSE	FINDINGS
Rico, Costales, Cabranes & Escudero, 1990	18 drug exposed newborns compared with 18 non exposed newborns.	Study compared serum osteocalcin in infants to determine possible drug related changes in serum levels.	Birth weights significantly reduced in drug exposed group ($p < .05$), drug-exposed infants had significantly reduced levels of osteocalcin ($p < .005$) as did their mothers. Results suggest a toxic effect of cocaine and heroin on osteoblasts accounting for lower birth weights and skeletal alterations in drug exposed infants.
Rivkin & Gilmore, 1989	1 case study.	Report of seizure.	Seizure reported in an infant due to environmentally acquired cocaine.
Rosenstein, Wheeler & Heid, 1990	100 infants with cocaine exposure.	Study used GU ultrasound to determine congenital renal abnormalities in drug exposed infants.	Routine renal ultrasounds not indicated in full-term neonates exposed to cocaine.
Ryan, Ehrlich & Finnegan, 1987	150 women divided into 3 groups. 1 group used heroin, methadone and cocaine, 1 group used heroin and methadone and 1 group used no drugs.	This study examined the effects of cocaine and poly drug exposure on the fetus and neonate.	Gestational age at birth similar across all three groups. The group using cocaine delivered infants with significantly lower birth weight, length, head circumference and Apgar scores.

STUDY	SAMPLE	PURPOSE	FINDINGS
Saylor, Lipa & Lee, 1991	15 cocaine exposed infants compared and followed with a control group for 12 months.	To identify infant behaviors and nursing skills which enhance parenting of cocaine exposed infants in the home.	Infants exposed to cocaine were SGA, and needed nonnutritive sucking, had excessive extensor tone, infections and irritability. The support system and organization of the home were predictive of the ability to sustain and maintain caregiving.
Shannon, Lacouture, Roa & Woolf, 1989	1,120 children seen at a pediatric hospital.	Determine the prevalence of cocaine exposure among children in the pediatric age group (0-21).	4.6% of all patients had drug tests positive for cocaine (indicating exposure within the last 48 hours). Of these, 52 patients total, 4 were neonates, 3 were infants, and 45 were adolescents.
Shih, Cone-Wesson & Reddix, 1988	18 neonates with known cocaine exposure matched with 18 neonates without exposure.	This study tested auditory brainstem responses to determine possible auditory and neurologic dysfunction.	Auditory brainstem responses from exposed infants show prolonged peak latencies and prolonged absolute latencies.

STUDY	SAMPLE	PURPOSE	FINDINGS
Streissguth, Grant, Barr, Brown, Martin, Mayock, Ramey & Moore, 1991	876 mothers retrospectively compared to demographic and social data.	To determine incidence and social characteristics associated with cocaine use in pregnant mothers.	Mothers at highest risk for cocaine use were black, single, separated or divorced, and had less than a high school education. Cocaine users were more likely to drink alcohol, smoke and take other illicit drugs.
Sturner, Sweeney, Callery, & Haley, 1991	6 case studies of cocaine related infant deaths.	To describe the effects of cocaine causing infant death.	Infant deaths were related to high dose related acute ingestion either by mother or passively through infant formula or to social neglect factors due to continuing cocaine abuse (traumatic compression asphyxia, malnutrition and dehydration, infection).
Telsey, Merrit & Dixon, 1989	Case study, 1 child.	Description of necrotizing enterocolitis in a cocaine exposed infant.	Suggestion that bowel infarction and necrotizing colitis may be related to intrauterine cocaine exposure.
Teske & Trese, 1987	Case study.	Ocular effects of cocaine exposure.	A cocaine exposed infant had retinopathy of pre-maturity with persistent hyper-plastic primary vitreous.

STUDY	SAMPLE	PURPOSE	FINDINGS
van de Bor, Walther & Ebrahimi, 1990	15 full term infants with known cocaine-exposure, matched with 22 non-exposed neonates.	To examine the effects of increased circulating catecholamines on cardiac output in cocaine exposed infants.	On the 1st day of life, cocaine exposed infants had significantly lower cardiac output and stroke volume and arterial blood pressure. By day 2 there were no significant differences between groups. Authors speculate that increased plasma norepinephrine is responsible for CV effects in cocaine exposed infants and that these effects decrease after excretion of cocaine and its metabolites.
van Baar, 1990	Infants with poly drug exposure matched with infants with no known exposure.	Comparison study between polydrug(including cocaine) exposed infants and non exposed infants.	Bayley Scales of Infant Development used to determine differences in development between drug exposed and non exposed infants. Some indication that infants who are drug exposed may have increased risk of language delay. No significant findings in areas of psychomotor development or behavioral development.

STUDY	SAMPLE	PURPOSE	FINDINGS
van de Bor, Walther & Sims, 1990	20 infants with cocaine exposure matched with 18 infants with no known exposure.	To examine the effects of enhanced circulating catecholamines on cerebral blood flow in exposed vs. non-exposed neonates.	Exposed infants had significantly increased flow velocities in pericallosal, internal carotid, and basilar arteries on day 1 of life, by day 2 there were no differences between the 2 groups. Indication that cocaine exposed infants may be at increased risk for Intracranial hemorrhage due to increased blood velocity in first day of life.
Zuckerman, et al, 1989	1226 mothers examined for cocaine and marijuana use.	To determine the effects of maternal use of cocaine and marijuana on fetal growth.	In mothers with positive urine toxicology for cocaine or marijuana, there was a significant difference (lower) in birthweight, length and head circumference ($p < .01$) between exposed and non drug exposed children. In mothers with only self reported drug use, there was no difference between groups.

STUDY	SAMPLE	PURPOSE	FINDINGS
Zuckerman, Maynard, Cabral, 1991	33 infants with similar gestational age, 8 exposed to cocaine prenatally.	To examine the incidence of RDS in a sample of cocaine exposed infants with controls for several variables.	Cocaine exposed infants had a decreased incidence of respiratory distress syndrome.

APPENDIX 2
INFORMED CONSENT

IRB# _____

LOYOLA UNIVERSITY OF CHICAGO
CHICAGO, IL
INFORMED CONSENT

Last Name _____

Date: _____

Project Title: The Experience of Foster Families Caring for Cocaine Exposed Infants

Director of Study: Sharon Jackson Barton, RN, MS, Ph.D Candidate

Family Information

1. This study examines the experience of foster families caring for cocaine exposed infants.
2. The researcher will interview you and any other interested adult family members about what it has been like to care for a cocaine exposed infant.
3. Your interview will be tape recorded and will last for approximately 45 minutes to 1 hour.
4. If at any time you would like to conclude the interview, your request will be immediately honored.
5. If you reveal any information you would not like to be included in the data analysis, that request will be honored.

6. If at any time, you decide not to participate in this research study, tell the researcher and the interview will be concluded.

RISKS

The only risk from taking part in this study is that you may feel tired about talking about the experience. You may decline to take part in the study at any time.

BENEFITS

You may perceive a benefit from being able to talk about the experience of being a foster family of a cocaine exposed infant. The researcher will be examining the experiences of many families caring for cocaine exposed infants. You may find that the information to be shared by the researcher is helpful in understanding your own experience.

ALTERNATIVES

You may decline to participate in this study at any time before, during or after the interview.

CONFIDENTIALITY

All information you share through interview is confidential. Your name will not be anywhere except this form. The audio tape of the interview will be coded by number only. Any information that would specifically identify you or your child will not be used. You will be known to the research study as a number only.

COMPENSATION

There is no compensation for participation in this study except for that derived from the experience of talking with the research investigator.

If any questions or concerns arise, the research investigator may be contacted:
Sharon Jackson Barton (312) 880-3345.

CONSENT

I have fully explained this research study to the participant. I have answered any questions to the best of my ability.

Sharon Jackson Barton, Research Investigator

INFORMED CONSENT

I have been fully informed of the research project and possible benefits and risks. I give permission for my participation in the study. I know that the research investigator will be available for any questions that I may have. If, at any time, I feel that I do not want to be included in this project, I will contact the research investigator or her chairperson. I understand that I am free to withdraw this consent and discontinue participation in this project at any time without prejudice. I have received a copy of this Informed Consent Document.

Signature of participant

Signature of research investigator

**APPENDIX 3
FOCUSED INTERVIEW SCHEDULE**

1. What has the experience of foster parenting (child's name) been like?
Probe: On a good day?
Probe: On a not so good day?
2. Have the foster children had any special health needs?
Probe: What kinds?
3. How does this baby compare with other children you have parented?
4. How do you manage the needs of your foster child?
5. What impact has fostering had on your family?
Probe: Your husband?
Probe: Other children in the household?
Probe: Other biological children?
Probe: Your extended family?
Probe: Your community?
6. What allows you to keep doing this?
Probe: What would make you stop, or take another child?
Probe: Where do you get your support?
7. What do you perceive to be the needs of your foster children?
8. What is your relationship with the foster care system or your particular agency?

APPENDIX 4
REPORT OF THE EXTERNAL AUDIT

	YES	NO
DESIGN		
1. Is the research question clearly stated?	X	
2. Is there evidence of protection of human subjects?	X	
METHOD		
1. Is there congruence between raw data and transcripts?	X	
2. Is data gathering process appropriate?	X	
3. Is sampling described?	X	
4. Is there evidence of developing instrumentation?	X	
5. Is purpose for selecting method clear?	X	
ANALYSIS		
1. Is data analysis apparent?	X	
2. Do examples represent the data?	X	
3. Have compatible units of analysis been selected?	X	
4. Do categories match emerging theory?	X	
5. Is there evidence that data saturation occurred?	X	
6. Is data analysis appropriate for the study?		
7. Is there unused or conflicting evidence?		X
8. Is significance for nursing stated?	X	
CREDIBILITY		
1. Is there evidence of member checking and/or preliminary validations (ongoing member checks)?	X	
2. Are raw data isomorphic with study being investigated?	X	
3. Are findings explicit?	X	
4. Has the audit uncovered unreported findings?		X
Signature of Auditor <i>Sandra J. Bunkas, RN, MS</i>		

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VITA

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Sharon Jackson Barton received the Bachelor's Degree in Social Work from the University of Illinois at Urbana-Champaign in 1972. She received a diploma in nursing from the Evanston Hospital School of Nursing in Evanston, Illinois in 1978. She completed the Master's Degree in Nursing from Rush University, Chicago Illinois in 1985.

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Barton has been a co-investigator on several research projects including "Negotiation of Care by Parent" and "Predictors of Quality of Life in Children and Families with Hemophilia." Research interests include the long term development of children exposed to cocaine prenatally and mother-infant interactions in infants

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APPROVAL SHEET

The dissertation submitted by Sharon Jackson Barton has been read and approved by the following committee:

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The final copies have been examined by the director of the dissertation and the signature which appears below verifies the fact that any necessary changes have been incorporated and that the dissertation is now given final approval by the Committee with reference to content and form.

The dissertation is therefore accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy.

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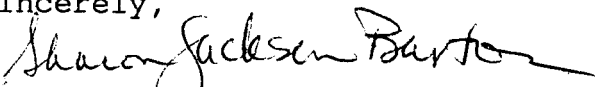
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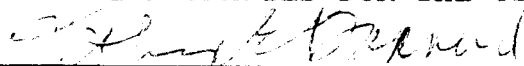
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