THE UNIVERSITY OF ALBERTA

MATERNAL ATTACHMENT TO THE INFANT WITH DOWN SYNDROME

by

Gail Diachuk

A THESIS
SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH
IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE
OF MASTER OF NURSING

FACULTY OF NURSING

EDMONTON, ALBERTA
SPRING, 1989

National Library
of Canada

Bibliothèque nationale
du Canada

Canadian Theses Service

Service des thèses canadiennes

Ottawa, Canada
K1A 0N4

ISBN 0-315-52908-3

THE UNIVERSITY OF ALBERTA

RELEASE FORM

NAME OF AUTHOR: Gail Diachuk

TITLE OF THESIS: Maternal Attachment to the Infant with Down Syndrome

DEGREE: Master of Nursing

YEAR THIS DEGREE GRANTED: Spring, 1989

Permission is hereby granted to THE UNIVERSITY OF ALBERTA LIBRARY to reproduce single copies of this thesis and to lend or sell such copies for private, scholarly or scientific research purposes only.

The author reserves other publication rights, and neither the thesis nor extensive extracts from it may be printed or otherwise reproduced without the author's written permission.

..M. Gail Diachuk..........
(Student's signature)

11 Coachman Place
Sherwood Park, Alberta
T8H 1C1

Date: April 24, 1989

THE UNIVERSITY OF ALBERTA

FACULTY OF GRADUATE STUDIES AND RESEARCH

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled Maternal Attachment to the Infant with Down Syndrome submitted by Gail Diachuk in partial fulfilment of the requirements for the degree of Master of Nursing.

Peggy Anne Field

Vangie Bergum

Brenda E. Munro

Date: 10 April 1989

Dedication

This thesis is dedicated to my family for the joyful, loving and pleasurable life that I gratefully share with them.

To my husband, Chris: My best friend. His patience, love and encouragement has inspired a sense of confidence in myself which has made this research possible.

To my son, Jesse: My first born. His cheerful and contented nature has allowed me to achieve a sense of fulfilment through both motherhood and graduate education.

To my daughter, Kristen: My inquisitive baby. Her soft and cuddly presence has been a warm reminder of the truly important things in life and has provided me with such sweet diversion during this study.

Abstract

It is common for parents to experience grief following the birth of a handicapped infant which may interfere with the development of a mother-child relationship. Children born with Down Syndrome will usually have physical, mental and social handicaps. The parents must learn to cope with their grief and adjust to having a handicapped child.

This qualitative study was conducted using a grounded theory approach to gain understanding of the process of maternal attachment to the infant with Down Syndrome. Data were collected by means of tape recorded interviews with mothers of infants with Down Syndrome.

A constant comparative method of analysis was used in the study to identify the process of maternal role formation following the birth of an infant with Down Syndrome. After the birth, the process of maternal role formation provided the mothers with a means for expressing their attachment to the infants. Although similarities were found with the normal process of maternal-infant attachment, as described in the literature, there were differences in the process of maternal role formation as a result of the birth of an abnormal infant. The grief experienced by these mothers appeared to delay the attachment process as the mothers needed time and energy to gain an understanding of the condition and accept the responsibility for caring for the infant. However, the presence of an abnormality in the infant did not prevent maternal-infant attachment over time for the mothers in this study.

The implications of the findings for nursing practice, education and research were discussed with a particular emphasis on the needs of the family in obstetrical and community health nursing.

Acknowledgements

I wish to express my sincere appreciation to the individuals who contributed to the undertaking and completion of this thesis.

To Dr. Peggy Anne Field, my thesis committee chairperson, for her encouragement and support throughout this research. Her patience and understanding of my needs as a mother of two young children helped to make this study possible.

Thankyou to the other members of my committee, Dr. Vangie Bergum for her interest in discussing my research study and Dr. Brenda Munro for her willingness to act as an examiner.

A special thank you to Dr. Elizabeth Ives for her support throughout my graduate studies. Her warmth and concern for me and my children has been greatly appreciated.

Financial support from the Dr. Jean C. Nelson Award, the Alberta Foundation for Nursing Research, and the Alberta Association of Registered Nurses is gratefully acknowledged.

Thank you to the five mothers who willingly and generously shared their time and experiences with me. It was indeed a pleasure to meet them and their children.

I would also like to thank my family and friends for encouraging me to strive for that which I truly desire. A special note of appreciation to my mother, Pat Reyda for being the type of nurse who inspired in others a sense of what nursing ought to be.

Finally, thank you to those people who babysat my children. A special note of thanks to the grandparents, Mike and Rose Diachuk, for giving me peace of mind knowing that my children were well cared for while I pursued my educational interests.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

Chapter I

INTRODUCTION

Down Syndrome is the most common form of a chromosomal disorder and can occur in any family, regardless of race, socio-economic status, or the education of the parents (Winzer, 1987). These children are usually affected with physical, mental and social handicaps. The birth of a handicapped infant results in a traumatic experience for the family and a challenging task for the health professional (Drotar, Baskiewicz, Irvin, Kennell, Klaus, 1975; Steele, 1987; Waechter, 1977). The family must learn to cope with their grief and adjust to a difficult situation and the health professionals involved in the care of the family must assist with this process.

Prior to the 1970's, parents often had two choices following the birth of a handicapped child: place the child in an institution or provide twenty-four hour care in the home with no supports (Taylor and Searle, 1987). From the late 1840's to the late 1960's, institutions for the mentally retarded developed and flourished (Taylor and Searle, 1987). Upon the advice of physicians and other professionals, many parents made the difficult decision to institutionalize their disabled children.

However, since the 1950's, the institutional model of care for the disabled has been waning (Taylor and Searle, 1987; Winzer, 1987). More educational and community support has been provided to parents to assist them in caring for their handicapped child in the home. At present, most parents choose to keep and care for their child with Down Syndrome in the home (Winzer, 1987). As the current trend towards societal acceptance of handicapped persons continues, more people will recognize children with Down Syndrome as valued members in the family and the community (Winzer, 1987).

Purpose of the Study

The purpose of this study was to develop a basic conceptualization of the process of maternal attachment to an infant with Down Syndrome by examining the ways in which mothers describe the process of attachment to their infants with Down Syndrome. Since only a few studies have explored maternal-infant attachment, it was intended that the results from this study would broaden the available knowledge on maternal-infant attachment.

Following the birth of a handicapped child, parents need the support of health professionals while making decisions about child care. In addition, the support by health professionals should continue to be provided to these families as they adjust to this difficult situation (Butani, 1984; Klaus and Kennell, 1982; Sahin, 1978; Waechter, 1977). Therefore, it is intended that health care professionals would be able to use the results of this study to assist them in planning intervention strategies to support mothers, and subsequently parents and families, during the process of attachment to their handicapped infants.

Statement of the Problem and Research Questions

The problem was to elicit and describe mothers' perceptions and experiences of attachment to their infants with Down Syndrome. The following research questions guided the investigative inquiry:

1) What are the factors which mothers describe as influencing the process of maternal-infant attachment following the birth of an infant with Down Syndrome?

2) How do mothers of infants with Down Syndrome describe their attachments to their infants at particular points in time?

3) How do mothers of infants with Down Syndrome describe their attachments to their infants over time?

Definition of Terms

Maternal-infant attachment. The current concept of maternal-infant attachment arose out of the work of Klaus and Kennell in the early 1970's. The original idea postulated that attachment was an event which occurred during a critical, sensitive period immediately after birth. The interaction between mother and newborn during this time period was thought to be essential for a healthy mother-child relationship. Currently, some of the literature refutes the notion of attachment being an event and describes it as a process (Stainton, 1986: Nelson, 1985; Gay, 1981). The process of maternal attachment to the infant has been identified as a dyadic relationship which is affected by both the mother's and the child's behavior (Gay, 1981; Gottlieb, 1978; Klaus and Kennel, 1982; Salariya and Cater, 1984). The terms bonding and attachment are often used interchangeably in the literature. However, an operational definition of each of these terms remains elusive.

The intent of this research was to describe mother's experiences of attachment to the young infant with Down Syndrome. In order to allow for the personal perspective of the mother's experience, attachment was not strictly defined by the researcher. Rather, maternal-infant attachment was assumed to have a broad colloquial meaning for each informant which reflected the developing growth of positive feelings on the part of the mother toward her infant, and included such dimensions as wanting to possess, to prolong, or to seek contact and to be proud of and to love her infant (Gottlieb, 1978).

Maternal role formation. The process in which the mother achieves competence in the role and integrates the mothering behaviors into her established role set, so that she is comfortable with her identity as a mother of a particular child (Mercer, 1985). It is important to note that the process of becoming a mother is more than just taking on a role, rather it is the "realization and acceptance" of being a mother (Bergum, 1989).

Down Syndrome

Historical Background

While there is evidence that Down Syndrome has existed for centuries, Dr. John Langdon Down is given credit for first describing the syndrome in 1866, which he referred to as "mongolian idiocy" (Down, 1866). Until recently the term "mongoloid" was used to describe individuals with this syndrome, however is no longer considered appropriate.

In 1959, a major breakthrough came in the field of genetics, when scientists in France (Lejeune, Gautier and Turpin, 1959) and in England (Jacob, Baikie, Court-Brown and Strong, 1959) discovered an extra somatic chromosome in the cells of individuals with Down Syndrome. It was not until 1971, at a conference in Paris, that a standardized chromosomal nomenclature using banding techniques, unequivocally identified the extra chromosomal material as a trisomy of the twenty first chromosome.

Description

The condition of Down Syndrome is usually recognized soon after birth from such signs as typical facial appearance, body configurations, and lack of muscle tone. More than fifty physical signs have been listed as characteristic of children with Down Syndrome (Winzer, 1987. See Figure 1 for common characteristics). Few children display all of the characteristics and the number of physical features a child displays bears no relationship to the degree of retardation (Winzer, 1987).

As the child with Down Syndrome develops, other problems often become apparent, including mental retardation, impaired health, physical handicaps, language delay and hearing impairment (Cunningham, 1982). About forty percent of children with Down

Cognitive level:
mild to profound
mental retardation

Stature:
below average

Muscles:
hypotonia

Skin:
thick, dry, rough
mottled or flushed

Heart:
congenital malformations
in one-third of patients

Abdomen:
prominent
umbilical hernia common

Head:
brachycephalic
flat occiput

Hair:
sparse, fine and soft

Face:
flat profile

Mouth:
thick, fissured lips
narrow palate

Teeth:
small
irregularly aligned
late erupting

Tongue:
protruding
furrowed

Nose:
low flat bridge
absent nasal cartilage

Ears:
small and low-set
overlapping letices
hearing impairments

Eyes:
epicanthic folds
Brushfield spots
strabismus common
nystagmus common

Hands:
short and broad
simian crease common
incurved little finger

Feet:
short and broad
excessive space between
first and second toe

Figure 1
Common Characteristics Associated with Down Syndrome
(Adapted from Winzer, 1987)

Syndrome have congenital heart disease, while structural defects such as atresias of the stomach, duodenum and trachea are common. These children are also highly susceptible to upper respiratory infections and gastroenteritis. The incidence of leukemia is about fifteen times greater than in normal children (Whaley and Wong, 1979). In recent years the life span of individuals with Down Syndrome has begun to approach that of the general population.

There are three major types of chromosomal abnormalities which cause Down Syndrome: Trisomy 21, mosaicism and translocation. Trisomy 21 accounts for about ninety-five percent of children with Down Syndrome and is caused by a nondisjunction of the twenty first pair of chromosomes during development of the egg or sperm or during early cell division of the fertilized egg (Winzer, 1987). Mosaicism accounts for about two percent of children with Down Syndrome. The extra chromosome is not present at fertilization, but results from faulty distribution of chromosomes in later cell divisions. These children have some normal cells and some cells with the extra chromosomal material. Some research has suggested that Down Syndrome children who possess some normal cells may present with fewer physical and mental problems (Hopkins, 1983).

A translocation of chromosome twenty one is the third type of Down Syndrome and is also rare. In one third of these cases, the extra chromosomal material is inherited from a normal parent who is a carrier of a balanced translocation (Cunningham, 1982). The other cases of translocation are due to spontaneous mutation. Extra material from the twenty-first pair of chromosomes is attached to another chromosome so that the child's chromosome count appears to be normal but upon closer examination is recognized to be abnormal.

Incidence and Etiology

Down Syndrome is known to occur in about 1 in 640 births (Winzer, 1987). Several hypotheses have been formulated to explain the occurrence of chromosomal nondisjunction found in Down Syndrome: viral infection (Anneren, Gronowitz, Kallander, Sundquist, 1986), radiation (Brown,1984), maternal thyroid antibodies, parental mosaicism, endocrine disorders and delayed fertilization (Milstein-Moscati and Becak, 1981). According to the literature, the results of testing these hypotheses have to date been inconclusive. However, there is adequate evidence to prove that the chances of having a Down Syndrome child increases dramatically with the age of the mother (Hook, 1981. See Table I for incidence rates

TABLE I

INCIDENCE OF DOWN SYNDROME AT BIRTH BY MATERNAL AGE AT TIME OF EXPECTED LIVEBIRTH

(Adapted from Hook, 1981)

MATERNAL AGE	DOWN SYNDROME AT BIRTH	CHROMOSOME ANOMALY AT BIRTH
-19	1/1550	1/500
20-24	1/1550	1/525-1/475
25-29	1/1050	1/475-1/400
30-33	1/700	1/385-1/250
34	1/500	1/260
35	1/385	1/204
36	1/294	1/164
37	1/227	1/130
38	1/175	1/103
39	1/137	1/82
40	1/106	1/65
41	1/82	1/51
45	1/30	1/20
49	1/11	1/8

by maternal ages). The research literature shows only a slight increase in the incidence of Down Sydrome with advanced paternal age (Stene, Fischer, Stene, Mikkelsen, Petersen, 1977; Matsumaga, Tonomura, Oishi, Kikuchi, 1978). In summary, while the underlying cause of chromosomal nondisjunction remains elusive, the cause of Down Syndrome is known to be the result of the trisomic nature of the twenty first chromosome.

The Evolution of Improved Care

In the past, it was thought that children with Down Syndrome had little potential for learning and should be institutionalized rather than be cared for in the home. However, the mental potential of children with Down Syndrome has shown a remarkable improvement over the last thirty years (Coleman and Olson, 1987). Intellectually, the child with Down Syndrome can fall anywhere in the spectrum from mild to profound retardation with most tending to be classed as moderately retarded (Winzer, 1987). Although evidence for the long-term benefits from infant stimulation programs for children with Down Syndrome is still being collected, there is no longer any doubt that some significant benefit is occurring (Coleman and Olson, 1987).

In addition, there is a present social trend away from institutionalization towards caring for handicapped children in the home. The mother usually provides most of the child care to the handicapped infant. Her ability to develp a positive relationship with the infant has the potential for influencing the care that the child receives from the family. The child's growth and development could be affected by the mother's ability to successfully care for the handicapped child.

Professionals in health care and education are being called upon to provide the necessary support to these parents to provide adequate care to their children. However, in order to know how to help these parents, health care professionals need to better understand the parental experiences following the birth of a handicapped child. As members of the health care team responsible for the follow-up care provided to these families, it is essential that nurses gain a better understanding of the experiences of these mothers and the factors which might affect the mother's relationship with the Down Syndrome child.

Chapter II

REVIEW OF THE LITERATURE

Although the birth of a child is a stressful event under normal circumstances, the birth of a handicapped infant precipitates a crisis for the parents (Steele, 1987). Both family and professionals involved in the birth are affected by the event. In a study which examined the early experience of mothers' with normal as compared to abnormal first-born infants, Hosack (1968) suggested that both sets of mothers experienced a crisis. However, mothers of normal infants experienced a developmental crisis whereas mothers of abnormal infants were thought to experience both a developmental crisis and accidental crisis simultaneously. Hosack (1968) found that mothers of handicapped infants coped better than mothers of normal infants. The researcher speculated that the child's handicap "brought out the best" in the mother's ability to cope and that extra support was provided to these mothers by family and the medical team.

A number of authors (Butani, 1984; Fleischman and Fryd, 1980; Giller, Rotnem, Hsia, Leigh, 1981; Klaus and Kennell, 1982; Sahin, 1978) have suggested that a multidisciplinary approach to health care should be provided to meet the extensive and ongoing needs of the family following the birth of the handicapped infant. In order to be able to assist the parents through the necessary process of adjustment, the health professional must have a clear understanding of what the parents are experiencing and the factors which might influence the parental experience. To date much of the literature in this area has been limited to professional conjecture.

In the review of selected research and descriptive literature relevant to the mother-child relationship following the birth of a handicapped child, it was necessary to examine a number of related topics. The following topics were reviewed and will be discussed in succeeding order within this chapter: the process of maternal-infant attachment, the interaction between maternal-infant attachment and maternal role attainment, parental responses to the birth of a handicapped infant, the parents' adjustment to having a handicapped child and the role of the health care worker to assist these parents.

Maternal-Infant Attachment

Maternal-infant attachment has been identified as a dyadic relationship which is affected by both the mother's and child's behaviour (Gay, 1981; Gottleib, 1978; Klaus and Kennell, 1982; Salariya and

Cater, 1984). The major concern regarding maternal-infant attachment is the need for a warm, consistent, nurturing relationship between a mother and her infant as a prerequisite for the healthy development of the child (Ainsworth, 1969; Bowlby, 1958; Campbell and Taylor, 1979; Klaus and Kennell, 1982). Indeed there exists a concern that child abuse and non-organic failure to thrive is more likely to occur when maternal-infant attachment is not present (Hurd, 1975; Kennell, 1987; Klaus and Kennell, 1982; O'Connor, Vietze, Sherrod, Sandler, Altemeier, 1980).

The work by Klaus and Kennell (1976) brought to the forefront the importance of bonding. Their work was based on ethological data from a variety of animal observations which suggested that there is species-specific maternal behaviour prior to, during and immediately after birth that leads to the mother's attachment to her offspring (Nelson, 1985). The question arose as to whether humans also have species-specific behaviors at critical periods of time that facilitate maternal-infant attachment.

The bonding theory states that maternal-infant contact after birth is necessary for the formation of the bond which provides the foundation for optimal future maternal behaviour and thus as a necessary antecedent of optimal child development (Lamb, 1982).

The terms bonding and attachment are often used interchangeably in the literature, however, a conceptual framework was presented by Gay (1981) to differentiate between the concepts of bonding and attachment. The conceptual framework posits that the attachment process must begin prior to bonding and perceptions of negative affect can result in termination of the attachment process. However, the bonding process permits only positive affect and can not be terminated (Gay, 1981). Since the attachment process includes both positive and negative affects in the developing mother-infant relationship, it is this process that needs further exploration to understand the factors that can influence the mother-child relationship.

In a literature review by Brady-Fryer (1988), it was found that considerable effort has been expended by a number of researchers to examine and interpret maternal "attachment" behaviors in response to early and/or extended infant contact. However a number of criticisms have been made regarding the methodological difficulties with the use of an experimental design for studying maternal-infant attachment. Some of the problems identified are small sample size, non-random assignment to experimental and control groups and artificial manipulation of data to establish differences between groups (Brady-Fryer, 1988; Lamb, 1982). However the major problem with this work is the validity of the measures of the dependent variable employed in the studies. The researchers rarely provide rationale for the measurement of behaviors used as indices of maternal attachment (Brady-Fryer, 1988; Campbell and Taylor, 1979; Lamb, 1982). In addition, most of the researchers did not describe the conceptual processes of attachment that was being studied. These studies seem to be describing attachment as an event which occurs at a particular point in time. It seems more likely that attachment in humans is not an event which must occur at a specific time period, rather that it is a process which occurs over a period of time (Bergum, 1989; Gay, 1981; Klaus and Kennell, 1983; Nelson, 1985; Stainton, 1986).

The need for further exploration of the concept of attachment has been addressed in a small number of studies, where the investigators looked at the mother's experiences of attachment to their infants. The process of maternal-infant attachment is thought to begin with the shared-body experience during pregnancy (Bergum, 1989; Stainton, 1985a), when the mother begins to identify herself as the mother of the fetus (Cranley, 1981; Rubin, 1975) and experiences an intense, emotional investment in their unborn child (Robson and Moss, 1970; Rubin, 1977). In qualitative research studies, mothers have indicated that feelings of attachment to the infant develop over time and are dependent on repeated interaction before and after birth (Gottleib, 1978; Robson and Moss, 1970; Rubin, 1984; Stainton, 1986).

In a qualitative study of maternal attachment in primiparas, Gottlieb (1978) found that time associated with personalized contact between mother and infant was an important factor affecting the attachment process. The aspects of contact time which were thought to be important were readiness for contact or type and amount of contact between mother and infant (Gottlieb, 1978). Gottlieb (1978) identified two other factors affecting attachment as positive input by others and physical well-being. While the study was exploratory in nature, the results provide a model from which to view the process of attachment and identify a few of the critical variables affecting the development of the process. Further research would be required to test the relationship of the identified factors to the attachment process.

In a quantitative study involving 30 primigravidas with normal infants, Avant (1981) was able to establish maternal anxiety as a potential factor affecting maternal attachment to the infant. An instrument was used to measure maternal attachment behaviors as a manifestation of maternal-infant attachment. Once again the concern exists as to whether the maternal behavioral indices accurately reflect maternal attachment. The researcher noted that more research must be done to gain further knowledge about the influences on maternal attachment.

Interaction Between the Attachment Process and Maternal Role Attainment

While no other literature was found which examined the factors affecting attachment, a theoretical framework was developed by Mercer (1981) for studying factors that impact on the maternal role. Rubin (1977) states that the maternal-infant attachment process occurs simultaneously with the maternal role attainment process, where each process is affected by and affects the other but no evidence is provided to prove the linkage. The interactions of the mother and infant influence the progression of the process of maternal role attainment so that most of the factors identified in the theoretical framework by Mercer (1981) were related to the characteristics and behaviors of both the mother and infant. If these two processes do affect one another, then it is likely that the factors that are influential on maternal role attainment will also be influential in affecting the maternal-infant attachment process.

In a review of the literature, Gordenuk (1976) found that mother's of handicapped children have a lowered self-esteem related to giving birth to a child that has a congenital defect. The author concluded that the birth of a handicapped child can hinder the development of the maternal role, since self esteem is a major factor in the attainment of the maternal role (Gordenuk, 1976; Mercer, 1981). While the relationship of self-esteem to maternal-infant attachment was not discussed, it is possible that if the two processes are linked then self-esteem might be one of the factors which might influence maternal attachment to the handicapped infant.

As the primary socializing agent of the child, the mother's sense of achievement rests more on the child's perfection than does the father's sense of achievement (Mardiros, 1982; Featherstone, 1980). Mardiros (1985) found that the birth of a handicapped child effects the mother's perception of her child-bearing role. The mother's described feelings of being unable to give birth to a "normal" child, which called into question their femininity (Mardiros, 1985). In an exploratory study by Majewski (1987), primiparas were found to rely on social support to help in the transition to the maternal role. However, in two studies involving mothers with handicapped infants, Mardiros (1982, 1985) noted that these mothers have difficulty seeking social support and tend to see themselves as alienated and isolated from society. The major source of social support identified by the mothers was other mothers of handicapped children (Mardiros, 1985). In the study of primiparas with normal infants, Majewski (1987) found that those mothers who identified non-immediate family members, such as a parent support group, as their major source of support tended to have more difficulty in making the transition to the maternal role than those who identified the spouse as most supportive. Therefore it seems possible that mothers of handicapped children might have difficulty with maternal role attainment. The process of maternal-infant attachment and the subsequent maternal care provided to the infant might be affected by the mother's perceptions of her success at maternal role attainment (Gordenuk, 1976; Rubin, 1977).

According to Mercer (1985) and Rubin (1977), the maternal role attainment process occurs in stages throughout the pregnancy and up to 10 months postpartum. If maternal-infant attachment is linked to maternal role attainment, then it is possible the attachment process also occurs up to 10 months postpartum. According to Goodman and Taylor (1979), attachment refers to the affectional tie between mother and infant that develops gradually during the first year of life. While no research was found which studied attachment beyond the first year of the infant's life, it seems possible that the attachment process continues throughout the life cycle of the child. As noted by Bergum (1989) the transformation of woman to mother may be a never ending process, "changing and developing each moment in the lives of women with children of varying ages - in the womb, infant, school age, adolescent, or adult".

Parental Responses to the Birth of a Handicapped Infant

In reviewing the literature on parental responses to the birth of a handicapped infant, it becomes apparent that much of the literature focuses on the grief process that the parents experience as a result of the loss of the normal child (Butani, 1984; Drotar, Baskiewicz, Irvin, Kennell, Klaus, 1975;

Fleischman and Fryd, 1980; Mercer, 1974; Solnit and Stark, 1961; Waechter, 1977). The reason for the extensive study of parental grief is the belief that parents who do not begin a successful resolution of their grief are unable to accept the reality of their infant, thus hindering the bonding and attachment process (Steele, 1987). In one research study, a hypothetical model of parental adaptation to the birth of an infant with a congenital malformation was developed from interviews with the parents of 20 children with congenital malformations (Drotar, Baskiewicz, Irvin, Kennell, Klaus, 1975). The first three stages of the model of parental adaptation were similar to the descriptions of the grief process found in the literature which includes such responses as shock, grief, anger, shame and denial. In an exploratory study to discover the factors involved with parental responses to the handicapped child, Waechter (1977) interviewed 50 parents of handicapped infants. The researcher found that parents experience an immediate response of withdrawal as a result of shock and grief, which can last from a few hours to several weeks. While the researcher did not try to prove that withdrawal would effect the attachment process, it has been assumed by several authors that separation does hinder the attachment process (Klaus and Kennell, 1982; Waechter, 1977; Winzer, 1987).

In another exploratory study, Mercer (1974) examined the maternal responses of 5 multigravidae to their infants with congenital defects during the first three months following the births. There was no evidence to suggest that maternal-infant attachment had increased during this period of time. Rather the researcher found that the proportions of attachment and aversion behaviors changed very little over the first three-month period (Mercer, 1974). A similar finding was presented in a study involving interviews with parents of infants with congenital defects. The researchers found that parental attachment to the infant does not occur during the stages of grief immediately following the infant's birth, rather that attachment occurs after the grief process (Drotar, Baskiewicz, Irvin, Kennell, Klaus, 1975). Steele (1987) notes that the initial grief process must be facilitated in order for the parents to relinquish ideal expectations of the infant and themselves so that attachment to the actual infant can begin to occur. However as noted by Censullo (1986) and Morgan (1987) complete grief resolution is a long-term process, and it encompasses plateau periods with exacerbations during subsequent hospitalizations, anniversaries and other moments of loss. It seems likely that the attachment process might be affected during periods of exacerbations of grief, especially if the events occur within the first year of the child's life.

Although most of the literature addresses handicapped children as a group, there is some evidence to suggest that children with visible physical defects or mental retardation make it more difficult for parents to adjust. Waechter (1977) found the type of defect that the child has is the major factor contributing to parental adjustment. Using research based literature, Carreto (1981) confirms the relevance of visible physical defects to the difficulties that mother's may experience in bonding to an affected child. In particular, it was found that facial defects tend to cause greater emotional reactions by the mother than less visible defects in their child. Other authors report that infants with feeding problems can interrupt the mother's ability to care for the child which can influence the mother-infant attachment process (Carreto, 1981; Waechter, 1977; Winzer, 1987). In a qualitative study, Waechter (1977) found that mothers who want to breastfeed but find the child unable to do so, can experience bonding difficulties with the child. In addition, separation will occur more frequently with a handicapped child due to the medical needs related to the handicap which may cause further problems with bonding.

In a quantitative study, using an open-ended questionnaire, Childs (1985) examined the feelings of 50 mothers after the birth of a retarded child and found similar maternal responses to those associated with the grief process described earlier. In addition, eight other feelings were identified by the respondents as occurring in the first three weeks following the birth of the retarded child: inferiority, questioning religious beliefs, confusion, death wish, loneliness, unloved, infanticide and helplessness. The researcher concluded that mothers of retarded children are at risk of being suicidal, experiencing marital difficulties and requiring additional support by doctors, nurses and counselors (Childs, 1985). Though these results might be indicative of the first three weeks following the infant's birth, the mothers in the study noted that many of these conflicts dissipate with time. The researcher suggested that the support by health professionals during this period of conflict could help allay certain conflicts related to guilt, inferiority, shame, confusion, anger and helplessness. However, more research is needed to determine the long-term effects of these early conflicts and the level of adjustment of the mother as impacted by support services (Childs, 1985).

Children with Down Syndrome have recognizable physical traits, mental retardation and delayed development. Other physical defects, such as congenital heart disease, duodenal atresia and otological problems can result in additional separation while the children are hospitalized for medical needs. Hypotonic muscles often leave the infant with a poor suck which can result in feeding difficulties. All of these abnormalities may be factors which can effect the maternal-child attachment and the mother's ability to adjust to having a handicapped child.

Parental Adjustment to the Handicapped Infant

Although both medical and nursing researchers have suggested the need to examine the parent's adjustment to having a handicapped child, there has been little research done (Klaus and Kennell, 1982; Sahin, 1978; Waechter, 1977). There is some research to support the notion that the pattern of interaction between mother and child can effect the chronic health of the child (Holaday, 1987). Underlying this notion is the idea that the mother-child interaction is a reflection of maternal-infant attachment. Based on quantitative research involving parents of critically ill infants, Steele (1987) found that attachment to the infant is influenced by the caretaking roles of the parents. In a qualitative study, Brady-Fryer (1988) found that mothers described more feelings of attachment to their preterm infant as they were able to take-on a greater role in the caretaking of the infant. Mardiros (1982, 1985) found that mothers of handicapped children tend to be the main caretaker of handicapped children in the home. These mothers found that their lives centered on the child and the handicap, while fathers experienced less role alterations as a result of having a handicapped child. Indeed, Mardiros (1985) found that although 68% of the mothers had planned to return to work after having their baby, only 8% actually had returned. The mother's explanations for not returning to work consistently related to the child's health needs related to the disability.

Two studies were found which examined the factors which influence the parental adjustment. In the study by Waechter (1977), 50 parents of children born with various physical anomalies were interviewed to identify the factors involved in parental response to the birth of a malformed child. The parents were interviewed within a few days after the birth of the child and follow-up interviews were conducted at three-month intervals. Waechter (1977) found that parents displayed similar emotional responses immediately following the crisis but that variations in response occurred within a short period of time after the grief process. The factors which contributed to the parental adjustment to having a handicapped child were identified by the researcher as parental strengths, parental experiences, family stability and the type of defect. In another exploratory study, twelve mothers identified the five major sources of stress and support experienced by the mothers when parenting a disabled child as: self, disabled child, husband, professionals, society and family/ friends (Mardiros, 1982). These findings confirmed the importance of parental strengths and family stability as factors which influence the mother's ability to parent the disabled child.

In a hypothetical model of parental adaptation developed from an exploratory study, the two final stages of the model were labelled adaptation and reorganization (Drotar, Baskiewicz, Irvin, Kennell, Klaus, 1975). The authors were unable to determine when these stages occurred after the initial stages of grief but stated that parental attachment to the child was associated with the stage of adaptation. Therefore the factors which influence the parent's adjustment to having a handicapped child may also be influential on the maternal-infant attachment process.

The Role of the Health Care Professional

A large number of research and descriptive studies have been published in the medical literature on the role of the health professional in telling the parents about the handicapped child's diagnosis (Antley and Hartlage, 1976; Braitman and Antley, 1978; Carr, 1970; Cunningham and Sloper, 1977; Drillien and Wilkinson, 1964; Edelstein and Strydom, 1981; Fleischman and Fryd, 1980; Fost, 1981; Gayton and Walker, 1974; Gilmore and Oates, 1977; Peuschel, 1985; Peuschel and Murphy, 1975; Shiono and Kadowaki, 1979; Stone, 1967). These authors presume that the health professionals approach to informing the parents will be a factor in the parental attachment to the child. However, only one of these studies provided some evidence of a correlation between the health care received by the mother and the mother's relationship with the child (Edelstein and Strydom, 1981).

The nursing literature that is written about the role of the health professional in helping parents of handicapped children tends to be either anecdotal comments about particular cases (Gerver, 1983; Kihlstrom, 1983; Lycett, 1982; Thomas, 1983; Veach, 1983) or descriptive literature (Butani, 1984; Greenswag, 1983; Sahin, 1978). Most of these authors state that health professionals can influence the maternal-infant attachment process. However, little research could be found to support the relationship between nursing care and the attachment process.

Summary

In summary, there has been very little literature on the effect of giving birth to a handicapped child on the maternal-infant attachment process. However, the literature which was found described the child's handicap as a factor that was likely to disrupt the process of maternal attachment to the infant (Butani, 1984; Klaus and Kennell, 1982; Mercer, 1974; Drotar, Baskiewicz, Irvin, Kennell, Klaus, 1975; Waechter, 1977; Winzer, 1987). Some of the factors which were thought to affect the attachment process were the parental responses to the birth of the handicapped child, the type of handicap, the parent's ability to adjust to the situation and the assistance that the parents received from health professionals. Most of the studies have been exploratory, seeking information about parental responses following the birth of a handicapped child. The researchers in the literature used negative parental responses to infer the probability of attachment problems. However, there was no study found which systematically sought information about maternal attachment to the handicapped infant from the maternal perspective. The purpose of this study was to seek an understanding of the process of maternal-infant attachment from the perspective of the mothers. This perspective is important, since maternal attitudes and perceptions will reflect the long-term maternal care provided for the handicapped infant.

Chapter III

METHOD

The purpose of this research was to elicit and describe mother's experiences of attachment to the infant with Down Syndrome. The few studies which have explored maternal-infant attachment have only partially developed the conceptualization of this process. Since this research is process-oriented, it is best suited for a qualitative approach that is exploratory and discovery-oriented (Reichardt and Cook, 1979). Qualitative research is most appropriate for examining questions dealing with subjective experience and perceptions, situational meaning and areas where there is little pre-existing knowledge (Chenitz and Swanson, 1986; Field and Morse, 1985; Morse, 1986; Reichardt and Cook, 1979). Therefore a qualitative method known as grounded theory (Glaser and Strauss, 1967) was employed in this study in order to gain a basic understanding of the process of attachment as experienced by mothers of infants with Down Syndrome.

Grounded Theory

Grounded theory is a highly systematic research approach for the collection and analysis of qualitative data for the purpose of generating explanatory theory that furthers the understanding of social phenomena (Chenitz and Swanson, 1986). A grounded theory approach is used in this study to guide data collection and data analysis. When employing this method, the researcher uses sequential inductive and deductive inquiry to analyze the data and develop a conceptual framework which should be testable. A grounded theory approach is used to search out factors and relate the factors into a conceptual framework which described the process of maternal-infant attachment. Field and Morse (1985, p. 10) suggest that "carefully designed research at the level of factor-searching and factor-relating will provide a sound descriptive base of nursing and nursing practice."

The aim of grounded theory is to discover and describe dominant processes in social phenomena. The theoretical explanation of the process is derived from the data, rather than verifying existing theory. A constant comparative method is used throughout data collection, coding and analysis to assist with theory generation. This method involves three major steps: concept formation, concept development and theoretical development (Stern, 1985).

The Constant Comparative Method

Concept formation

All of the initial interviews and observations were transcribed by the researcher. The other interviews were transcribed by another person but the researcher reviewed all of the tapes with the transcriptions to insure accuracy of the transcriptions. While the transcriptions were being reviewed the researcher thought about the data, coded it and interspersed the interview data with hypotheses derived from the codes. According to Stern (1985), coding the data means labeling it to note what is going on, by choosing code words that indicate action. A grounded theory approach uses constant comparative analysis, where all pieces of data are compared with all other pieces of data. As the coded data was compared, patterns or categories become evident which helped the researcher to organize the data. This process of comparison and organization of data then leads to concept formation (Corbin, 1986; Stern, 1985). The researcher made hypotheses concerning the categories to which the data belonged. As more data was collected, the researcher asked questions about the data to clarify the choice of category to which the data belonged. The categories were either supported or disproved by collecting more data to determine whether the data fitted in a particular category. The comparative search for more data continued until unique categories no longer appeared and the categories appeared to be saturated with data. Saturation of categories provided the evidence that these categories were part of the framework being generated from the data (Stern, 1985).

Concept development

Three processes suggested by Stern (1985) were used to develop the concept and discover the core variable to which all other factors were related. The three processes are:

1. reducing categories by identifying linkages between categories to establish a higher-order category that describes several original categories.
2. selectively sampling the literature to develop the elements of the conceptual framework.
3. selectively sampling the data by seeking out more data to explain the linkages between the higher-order category and the literature.

The end result of these three processes was a conceptual framework which the researcher then proceeded to verify by using secondary data from additional sources.

Theoretical development

Theoretical development occurred as the researcher clarified the conceptual framework by using the theoretical codes described by Glaser (1978). These codes helped the researcher to diagram the data into processes that could be explained by the researcher. The researcher wrote down memos which reflected ideas about the interrelationships of the data as they were formulated. According to Stern (1985), these memos are an important aspect of theoretical development. The memos were sorted and ordered to help the researcher to establish the theoretical framework under study.

The Sample

In qualitative research non-probability sampling techniques is most useful where the researcher is interested in gaining an understanding of a concept and a description of a setting (Morse, 1986). The main assumption in non-probability sampling is that all members of a population are not equally informed about the knowledge being sought by the researcher (Morse, 1986). In addition, some members are better able to communicate the knowledge that the researcher is seeking to understand. A good informant should be willing and able to communicate and share with the researcher knowledge of their first hand experiences related to the topic of study. For this study, informants were selected based on their recent experience in becoming the mother of an infant with Down Syndrome. The sample size was limited due to the large amount of data obtained through in-depth interviews. Stern (1985) suggests that three informants may be adequate for a grounded theory approach, if the informants are knowledgeable, willing to share their experience and able to provide the researcher with adequate information. It was expected that 4-6 mothers of infants with Down Syndrome might be required to gain adequate information. Four informants were selected with assistance from a genetic associate and a medical geneticist at the genetics clinic.

It became apparent from the literature review that the maternal-infant attachment process begins during pregnancy. However following the birth of a handicapped child, it appeared that the grief process might interfere with attachment. Therefore it seemed important to explore maternal-infant attachment in these early months after the infant's birth. Due to the small population from which the sample could be drawn, the researcher attempted to select mothers with infants between the ages of one to six months, at the time of the first interview. The following selection criteria were employed in determining the appropriateness of the sample for this study.

The Sample Selection Criteria

A potential subject had to:

1) speak fluent English

2) reside in or near to the city where the study was conducted with the father of the infant with Down Syndrome

3) be willing to participate in at least three interviews with the researcher over a period of three to four months

4) have delivered her first infant with Down Syndrome within one to six months prior to admission into the study. In addition, the infant must be likely to survive the first year of life.

5) have not fitted the criteria for an amniocentesis during the pregnancy, to ensure that the diagnosis of Down Syndrome was unexpected.

The final criteria for sample selection was altered slightly since there was some difficulty in obtaining an adequate sample with the original sample selection criteria. There were only two potential subjects that fitted this original criteria. While both of these subjects were included in the sample, it was necessary to find additional subjects for the study.

Changes to Sample Selection Criteria

The final criteria listed above was changed to:

5. have not had a positive amniocentesis during the pregnancy, to ensure that the diagnosis of Down Syndrome was unexpected.
6. have no obstetrical history or family history which could suggest the possibility of a chromosomal anomaly.

The importance of the fifth criteria in the original sample selection criteria was to insure that the birth of the infant with Down Syndrome was unexpected. The changes that were made to this criteria did not alter the unexpected nature of the handicap.

Non-random Sampling Technique Used in Study

A convenience sample of four mothers was selected from a population of 11 women who had given birth to infants with Down Syndrome in the six months prior to the initial interviews. The records of these 11 births were registered with the genetics clinic and were made known to the researcher. However, four of these families resided outside the area designated for the study and were excluded by the sample selection criteria. Another mother did not fit the selection criteria as she had a prior obstetrical history which suggested the possiblity of a chromosomal anomaly.

Two other mothers who were not included in the sample did fit the changed sample selection criteria. However, nurses in the community involved in the care of these families decided that it was inappropriate for these mothers to be approached about entering the study. The nurses believed both these mothers were having some difficulty accepting the birth of a child with Down Syndrome and that the relationship between the nurses and these mothers would be adversely affected if the mothers were approached to be in the study. These nurses acted as gatekeepers preventing the researcher from approaching these mothers to ask if they would participate in the study.

The two mothers who fitted the original sample selection criteria agreed to participate in the study. Following the changes to the sample selection criteria, an additional two mothers were informed about the study by the genetic associate at the genetics clinic. Both of these mothers also agreed to participate in the study. Once admitted to the study none of the four informants withdrew from the study.

In addition, the researcher received ethical clearance to access interviewed data involving the mother of an infant with Down Syndrome from another study. The data from these interviews was used as a secondary source to validate information from the primary informants interviewed by the researcher.

Characteristics of Selected Informants

Demographic Data

The four mothers interviewed for this study resided in the same urban area at the time of the interviews. One of the mothers moved outside of the city following the second interview but continued to communicate by phone and in writing with the researcher after the move. All of the informants were married to the fathers of the infants. The number of years married in the present relationship ranged from 1 to 12 years. Three of the women were married for the first time and for the other mother it was a second marriage.

All of the parents of the infants were Caucasian. The ages of the mothers ranged from 31 to 38 years (mean 35) and the ages of the fathers ranged from 31 to 40 years (mean 35).

All of the mothers had completed high school. One mother had completed a two year college program. One mother had completed two years in an undergraduate degree with a major in sociology. The last mother had completed two undergraduate degrees with a major in special education. Two of the mothers elected to be at home during the pregnancy and planned to remain at home with their children. The other two mothers had been employed during the pregnancy, one as a teacher and the other as a government clerk. At the time of the first interview, both of these mothers thought they would remain at home with their infant. However, both of them decided for financial reasons that it was necessary for them to return to work. One of the mothers returned to work when the infant was four months old and the other mother planned to return to work when the baby was just over one year of age. All of the fathers were employed at the time of the study.

Characteristics of Previous Pregnancies

All of the informants were multiparas: three of the mothers had one other normal child and the fourth mother had three other normal children by a previous marriage. None of the mothers had experienced a miscarriage, although one mother had experienced a therapeutic abortion.

All of the siblings from the current marriages were living in the homes of the study mothers. These siblings ranged in age from 2 to 10 years. The three half-siblings from the previous marriage of the one mother lived with their father in another country and ranged in age from 11 to 18 years.

Characteristics of the Current Pregnancy and Delivery

Three of the pregnancies which produced an infant with Down Syndrome were planned and one pregnancy was unplanned (See Table II). The mother with the unplanned pregnancy considered terminating the pregnancy with an abortion. This mother had three older children by a previous marriage and was not married when she became pregnant with the current pregnancy. However, she was in a stable common-law relationship with the father of the child for a number of years before the current pregnancy occurred. They had not been using any form of birth control because the father was thought to be sterile due to a previous injury. Although the mother was unsure about having the infant, the father's excitement about the conception and his enthusiasm in

TABLE II

CHARACTERISTICS OF THE CURRENT PREGNANCY AND DELIVERY

Subject	Planned Pregnancy	Problems in Pregnancy	Delivery	Gestation (in weeks)
1	yes	none	vaginal	40
2	yes	poor weight gain in last trimester	vaginal	38+
3	yes	premature labour	vaginal forceps	37
4	no	lower back pain	induced vaginal saddleblock	40

partaking in the event convinced the mother to continue with the pregnancy.

Each of the women stated that they had a very good pregnancy. The mother with the unplanned pregnancy experienced severe backaches throughout the latter part of the pregnancy due to a previous back injury. Also a number of ultrasounds were done throughout this pregnancy since the mother's expected date of delivery was questionable. Another mother experienced poor weight gain in the last three months of her pregnancy but no ultrasounds were done and the family doctor did not seem concerned by the mother's weight gain.

Two of the women were eligible for amniocentesis because of advanced maternal age. Both of these women chose not to have the test. One mother felt that she would not have an abortion to terminate the pregnancy if something was found to be wrong with the fetus. This mother felt that she did not want to know if something was wrong as she would only worry throughout the remainder of the pregnancy. The other mother who could have had an amniocentesis was living in another country at the time when the test should have been done for prenatal diagnosis. She chose not to have the test because of the high cost involved which she would have had to pay herself.

Two of the mothers had quick vaginal deliveries which were described as easier than their previous deliveries. One mother went into premature labour at 37 weeks which resulted in fetal distress and the use of forceps to hurry up the delivery process. The fourth mother had an induction due to ongoing back pain with a saddleblock to ease the back pain upon her request. A quick vaginal delivery ensued. All of the mothers were able to see and touch their infants briefly after the delivery before the infants were removed to the nursery.

Two of the mothers delivered their infants at community-based hospitals. One of these mothers was discharged within twenty four hours after the delivery upon her request because the baby was immediately transferred to the NICU at another community-based hospital. This mother had access to transportation and was able to visit her infant regularly at the hospital.

The two other mothers had their infants at a university-based hospital. Both of these mothers remained in the hospital with their infants for one week after the delivery.

Characteristics of the Infants with Down Syndrome

As shown in Table III, there were three females and one male infant in the study group. Only one of

TABLE III

CHARACTERISTICS OF INFANTS

Infant	Sex	Birth Weight (pounds-ounces)	Gestation (in weeks)	Problems	Length of Hospital Stay
1	female	7-14	40	-chromosome 21 translocation -heart defect (VSD) -rehospitalized for URI at 6 months	-7 days -18 days
2	female	4-9	38+	-Trisomy 21 -heart defects (ASD and VSD) -opthalmic problems -rehospitalized for croup at 5 months and URI at 7 months	-6 weeks -3 days -1 week
3	female	4-14	37	-Trisomy 21 -poor suck	-5 days
4	male	7-8	40	-Trisomy 21	-7 days

VSD- ventricular septal defect
ASD- atrial septal defect
URI- upper respiratory infection

the infants was placed in an NICU following the birth. Two of the infants were diagnosed with heart defects. The gestational ages ranged from 37 weeks to 40 weeks. The birth weights ranged from 4 pounds-9 ounces to 7 pounds-14 ounces.

All of the infants were diagnosed with Down Syndrome either at birth or immediately following the birth. Either one or both parents were informed of the diagnosis within a few hours after the birth. Chromosome tests confirmed the diagnosis within a few weeks following the initial diagnosis. Three of the infants have Trisomy 21 and the fourth has a translocation of chromosome 21.

The two larger infants required no additional support after birth and the mother's experienced little difficulty with the feedings. Both of these infants were bottle fed a regular infant formula. One of these infants was diagnosed with a heart defect but it was felt at that time that the repair would not be required until the child was about three years of age. Although both infants are hypotonic, no other major abnormalities were diagnosed.

One of the study infants was premature and weighed 4 pounds-14 ounces. Following the birth, the mother was attempting to breastfeed the infant but the baby was lethargic and had a poor suck. The baby received breast milk from a bottle at the start of a feeding and would finish the feeding with the help of a nipple placed over the breast. Although the baby had poor weight gain, the mother and infant were discharged at five days, due to a nurse's strike at the hospital. The baby began to gain weight following discharge and by two months of age was able to breastfeed successfully without assistance. Other than hypotonia, no other major abnormalities have been diagnosed.

The smallest infant was born nine days early and weighed 4 pounds-9 ounces. The baby was initially transferred to a community-based NICU. However on the fourth day it was transferred to a university-based NICU for treatment of suspected congestive heart failure. Following twenty-four hours of observation, the infant's medication was changed and the baby recovered enough to be returned to the community-based NICU. An echogram revealed an atrial septal defect (ASD) and a ventricular septal defect (VSD) which would need repair as soon as the child was stable and had gained some weight. The infant was discharged from hospital at six weeks of age. The infant also has protruding eyes requiring an opthalmic lubricant because the eye lids do not properly close over the orbits. Although there was some suspicion that the child's vision might be abnormal, an eye exam revealed normal vision. The infant was initially given breast milk by gavage and bottle feedings for the first two months but is now on an enriched formula in a bottle with an enlarged hole to assist with weight gain.

The two infants with heart defects were both rehospitalized with respiratory problems. The larger infant was treated in hospital for 18 days at about 6 months of age with bronchiolitis. Following discharge a repeat echogram was done and revealed that the VSD was becoming larger and required a repair as soon as possible. The smaller infant was rehospitalized for 3 days at 5 months of age with croup and again for 1 week at 7 months of age for pneumonia. A cardiac catheterization following the second hospitalization revealed an increasing need for heart surgery to repair the heart defects. At the end of the study these two infants were seven months and nine months old and were on the waiting list for cardiac surgery.

The Setting

To gain an understanding of the participants experience it is necessary to conduct qualitative research in the natural setting of the participants

(Field and Morse, 1985; Mishler, 1979; Stern, 1985). In-depth interviews were used to collect data relevant to the process of maternal-infant attachment. Nine of the eleven interviews were conducted at the homes of the informants. The home interviews were usually conducted in either the living room or the dining area, at the preference of the informant.

Two of the final interviews were done over the phone, rather than at the home. In both of these cases, the interviews were for the purpose of clarification of specific data and verification of some of the researcher's early findings.

A secondary informant was used for verification of the researcher's findings following all of the interviews with the primary informants. At the informant's request this interview occurred in the backyard of her home.

The secondary data was obtained from transcripts of interviews which formed part of a previous study and was used to validate the primary data. These interviews involving a mother of an infant with Down Syndrome had been done over the phone by a nurse.

Data Collection

Interviews and Observations

Data were collected using field techniques consisting of interviews and observations. A guided interview was used to facilitate the process of exploration about the participants' experiences. The researcher asked the participants open-ended questions that related to the topic of study and probing questions were used to facilitate further discussion and clarification of subject responses (Appendix A). The subjects' responses guided the direction of the interview, depending on the knowledge and meaning that was gained by the researcher. The researcher took on the role of learner while asking the informants to teach the researcher about their experience.

Two to three interviews, each lasting approximately 60 to 90 minutes were conducted with each informant over a period of two to five months. The interview schedule for the mothers of these infants varied according to the age of the infant upon entry into the study (See Table IV). All of the interviews were recorded and the tapes were then transcribed for data analysis. The data analysis of one interview was done prior to the next interview to assist the researcher to understand the direction

TABLE IV

AGE OF INFANT (IN WEEKS) AT TIME OF INTERVIEW

Infant	Age of infant at each interview		
	One	Two	Three
1	10	16	32
2	28	34	—
3	8	13	19
4	28	32	44

that the interviews were taking. In addition the ongoing data analysis assisted the researcher with the preparation of questions for subsequent interviews to clarify data that was previously given by the informants. Informal telephone interviews were held with two of the informants following the final home interviews. These telephone conversations were used to clarify information which was given during previous interviews and to verify some of the researcher's findings.

All of the interviews were conducted during the day at mutually convenient times for both the informant and the researcher. Therefore the father's were usually at work during the interviews. A father of one of the infants was present at only one interview. This father chose to sit in another room for most of the interview. However, on a couple of occasions during the interview he did contribute some personal thoughts on his experience as the parent of an infant with Down Syndrome.

Since maternal interactions with the child may be linked to maternal-infant attachment (Avant, 1981; Rubin, 1977), the researcher requested that the infant with Down Syndrome be present during at least one of the interviews with the mothers. The infants were present at all of the home interviews and mother-infant interaction were observed by the researcher. A description of the interactions were recorded by the researcher immediately following the interviews. The researcher also recorded personal impressions and reflections following each interview. In addition, one of the informants kept personal notes of her feelings and concerns during the early months with her baby. These maternal reflections were shared with the researcher.

Quantitative Data

A diagnostic tool known as the Mother-Child Relationship Evaluation (MCRE) was given to the mothers in this study. Since the process of attachment is thought to occur over time, the instrument was supposed to be given at the time of the last interview. However, the instrument was not received until after all of the interviews had been completed. Therefore at the time of the last interview the researcher informed the mothers that the instrument would be sent to them by mail when it arrived. The instrument was received about one month after the last interview and was sent to the mothers with a prestamped, self-addressed envelope to be completed and returned by the mothers at their earliest convenience. Three of the mothers returned the questionnaire within a couple of weeks after receiving it in the mail. The researcher spoke to the fourth mother over the phone to ask that the questionnaire be completed and returned as soon as possible. The mother apologised for not having returned the questionnaire but said that she was having marital difficulties which were consuming most of her energy. Although the mother said she would send it right away, it was never received by the researcher.

The MCRE is a self-report personality instrument which utilizes Likert-type scales to assess four maternal attitudes relevant to the mother-child relationship. The maternal responses to 48 statements sampling child-rearing attitudes result in four attitude scores: Acceptance, Overprotection, Overindulgence and Rejection. The instrument is easily administered with individuals or groups and takes about 15 to 20 minutes to complete. The manual reports reliability data based on a split-half technique, using Pearson product moment correlations applied to first-half versus second-half scale scores. Based on a study of 80 middle class mothers, reliability coefficients were .57 for Acceptance, .53 for Overprotection, .41 for Overindulgence, and .47 for Rejection (Roth, 1984). Roth (1984) notes that because these coefficients are based on half-scales of only six items they may be a lower-bound estimate of reliability. The construct validity of the instrument has to date been supported by the few studies which have used the MCRE (Low, 1984). The findings from these studies support the notion that overprotection, overindulgence and rejection are all related forms of maternal rejection and are distinct from acceptance as measured by this instrument (Low, 1984). The manual also cites evidence for the validity of the instrument based on intercorrelations between scales. The mean coefficient of correlation was -.55, with the Overprotection and Overindulgence scales appearing to be most closely related to nonacceptance attitudes. It was expected that this quantitative data might offer verification of the observed and reported level of maternal-child attachment that had developed by the time of the final interview.

Ethical Consideration

A proposal for this research study was submitted for ethical approval from the University of Alberta Faculty of Nursing Ethics Review Committee and the institution from which the study sample was obtained. Following ethical clearance, potential subjects who met the proposed study criteria were informed of the study by a genetic associate at the genetics clinic. After agreeing to learn more about the study, an introductory letter (Appendix B) about the study and the researcher were sent to those mothers who were interested in participating in the study. The researcher was informed of the names and phone numbers of interested potential subjects. A phone call was made to these persons by the researcher to discuss the study in detail and to provide an opportunity for questions and answers about the study (See Appendix C for Sample Telephone Statement). An initial interview was arranged with interested subjects, and informed consents were signed at the beginning of the first interview (Appendix D). The interviews were conducted in the subject's home, and were arranged for the subject's comfort and convenience. The researcher assured the participants that any interview would be discontinued upon their request and that they might choose to leave the study at any time. This right however, was never exercised by any of the mothers.

Several measures were undertaken to protect the identity of the participants. Code numbers were assigned to the tapes and transcripts to insure subject anonymity. All of the audio tapes were kept secured by the researcher and erased at the completion of the study. The interview transcripts identified by the code numbers will be kept in a locked file by the researcher for no longer than five years, at which time they too will be destroyed. To protect the participants' identities, pseudonyms were assigned to each of the informants when reporting the verbatim statements used in the final report.

At the study's inception, provisions were made for the referral of informants who requested additional assistance in dealing with their infant with Down Syndrome to either the social worker or medical geneticist at the genetics clinic. One of the mothers did request such assistance and was referred to one of the medical geneticists.

In the event that child abuse or neglect was suspected, the researcher would have discussed her concerns with the mother and requested that the mother seek assistance from social services. The researcher informed the mother of the legal responsibility on the part of the researcher to inform social services of cases of child abuse or neglect. However, the researcher had no concerns of this type with any of the informants in the study.

Reliability and Validity

Qualitative research is frequently viewed as failing to achieve rigor in scientific research in relation to reliability, validity and objectivity. However, the assessment of rigor in qualitative research is different from the conventional ways of assessing the reliability and validity of a quantitative study (Glaser and Strauss, 1966; Sandelowski, 1986). The term "credibility" was used by Glaser and Strauss (1966) to describe the criteria for judging qualitative research and analysis. Several methodological means were used in this study to increase the credibility of the results.

The credibility of grounded theory resides in the accurate representation of the human experiences as they are lived and perceived by subjects. The investigators ability to describe and interpret the experiences under study can be affected by the investigator-subject relationship. Therefore the researcher was aware of the need to develop a trusting relationship with the subjects so that their personal experiences would be shared openly. At the same time it was important that the subjects recognized the researcher as someone wanting to learn about their experiences rather than having the knowledge to alter the experience. The role of learner helped the researcher maintain the distance required to allow for meaningful interpretation of the subjects' experiences.

The researcher was introduced as a graduate nursing student with some experience in the field of genetics. Chenitz and Swanson (1986) note that people are more willing to reveal content to nurses than to other people. All of the mothers said that it helped them to share their experience with the researcher knowing that the researcher had worked with other woman who had infants with Down Syndrome. All of the mothers talked freely with the researcher and shared their thoughts and feelings openly. The unstructured interview format presented minimal risk to the validity of the data obtained by allowing the interview to remain subject-oriented rather than researcher-defined (Field and Morse, 1985). However, the use of guiding questions to assist with data collection helped the mothers in sharing their experiences. At times the mothers would pose questions to the researcher which the researcher would answer, in order to maintain a reciprocal relationship with the informant. Generally the mothers were already knowledgable about the subject being asked but were seeking reassurance that they had accurate information. Therefore the researcher rarely had to take on the role of teacher thus minimizing any influence on the subject's behavior.

The social context under which the data was gathered is important in establishing reliability and validity of data (Field and Morse, 1985). The home interviews promoted a relaxed, non-formal atmosphere which allowed the participants to openly share their experiences of being the mother of an infant with Down Syndrome. In addition, the setting offered the researcher greater opportunity to observe the natural interactions between mother and infant, siblings and infant and on one occasion, father and infant.

The purposive sampling of informants who were knowledgeable and involved in the area of inquiry enhanced the internal validity of the data obtained in this study. Since the mother's experiences had either recently occurred or were currently taking place, there was little chance of error through recall. None of the mothers who were approached about the study refused to participate in the study or withdrew from the study.

Mothers experiencing difficulties with acceptance might have been good representatives of the extreme cases that are helpful for verification of the findings in grounded theory. However, this form of verification was not possible in this study, as the researcher was denied access to two mothers experiencing problems with acceptance. The mothers who agreed to participate were all showing evidence of acceptance of their infants.

The validity of the information is increased by verifying the data with information from several sources (Field and Morse, 1985). Triangulation allows for the collection and comparison of different forms of data relating to the same phenomenon. While triangulation techniques may be more time consuming, the comparative data which is obtained can provide a validity check and give "added depth to the description of the social meanings involved in a setting" (Hammersley and Atkinson, 1983). In triangulation, then, links between concepts and indicators are checked by recourse to other indicators. Data must never be taken at face value, rather the similarities and the differences of the results from these techniques provide more than a check of whether the inferences are valid but also assist in discovering which inferences are valid (Hammersley and Atkinson, 1983).

In this study a guided interview was used to elicit the maternal experiences and feelings regarding the developing maternal-infant relationship following the birth of an infant with Down Syndrome.

In addition, fieldnotes were kept of the researcher's own impressions and reflections following both the interviews and the observed mother-infant interactions. Finally, three of the informants completed the Mother-Child Relationship Evaluation (MCRE), to assess four maternal attitudes relevant to the mother-child relationship.

The constant comparative method used in grounded theory requires the constant coding and comparison of all data to discover similarities and differences between an individual's experiences and the other subjects' experiences. The four subjects interviewed in this study acted as four different sources. Therefore the verification of data with information from several sources is inherent in the process of grounded theory.

Additional sources were used to obtain further data to verify the information obtained from these primary informants. The transcripts of a series of interviews with a mother of an infant with Down Syndrome from a previous study were analyzed to validate the findings of this study. Verbatim accounts from this interview have been included along with the verbatim accounts of the primary informants to substantiate the categories which were used to develop the conceptual framework describing maternal-infant attachment identified in this study.

Sandelowski (1986) states that a qualitative study is credible when it presents such faithful interpretations of a human experience that the people having that experience immediately recognize it as their own. Participant review was used to test this form of verification. Two of the mothers were asked to verify specific parts of the early findings. A third mother reviewed the completed conceptual framework and agreed that it accurately depicted her experience.

Further verification was done by discussing the findings with a nursing colleague who is also the mother of a six year old daughter with Down Syndrome. This secondary informant reviewed the conceptual framework and stated that it was an accurate reflection of the process which she experienced after having an infant with Down Syndrome.

According to Glaser and Strauss (1966), the credibility of the products of grounded theory are influenced by the trust that a researcher has in one's own credible knowledge. The researcher's personal experience in the data collection and analysis for this study permitted her to systematically scrutinize the data and trust the accuracy of the conceptual framework which emerged from the data.

Unlike quantitative research, replication of this study would not necessarily result in the discovery of the same conceptual framework. The uniqueness of human situations is emphasized in qualitative research (Sandelowski, 1986). In addition, no two researchers would analyze the same set of data in exactly the same way. However, comparable findings in future studies of a similar nature would provide the criterion of rigor for the qualitative findings in this study.

Chapter IV

FINDINGS AND DISCUSSION

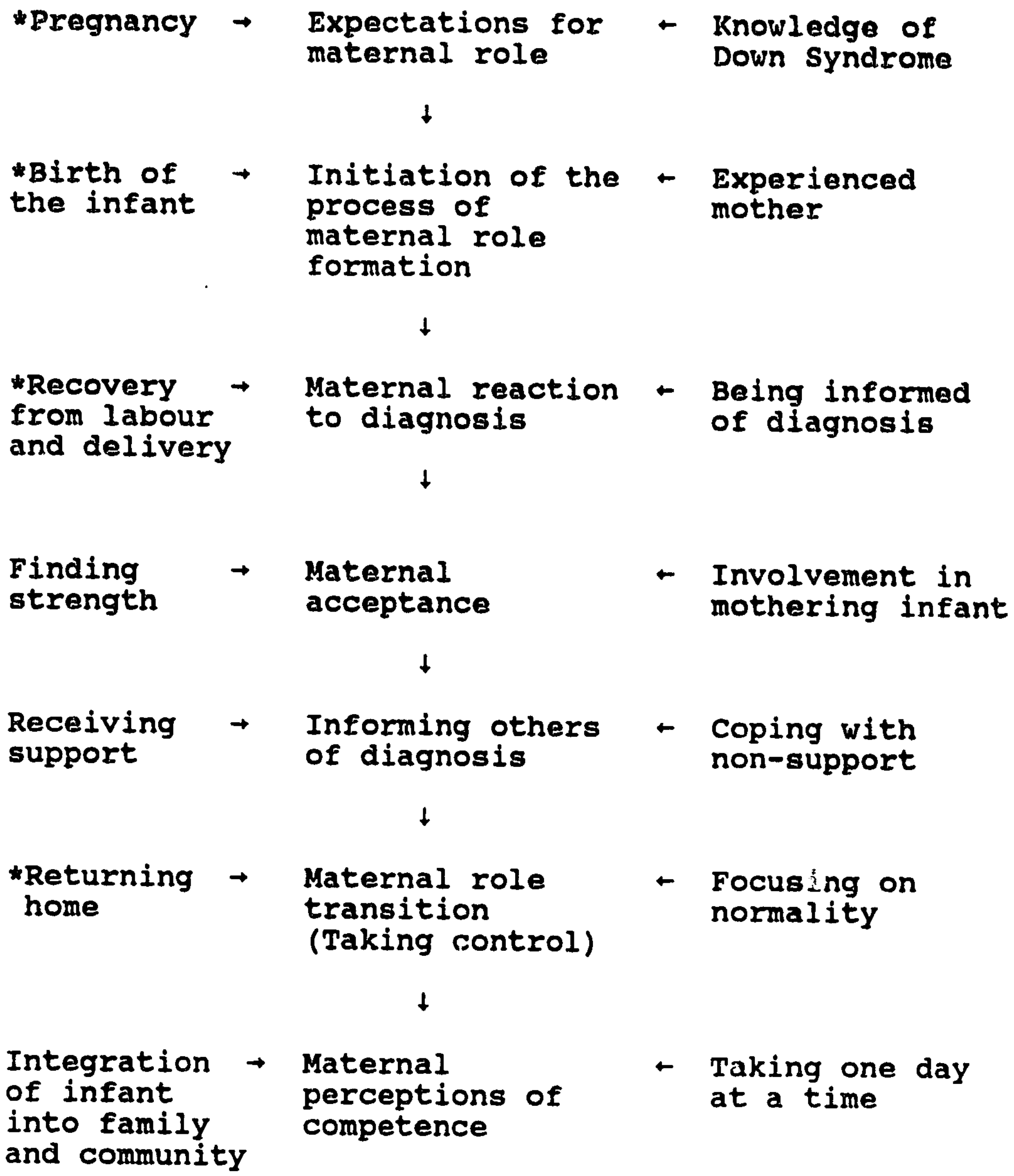
The results of the data analysis will be presented in this chapter accompanied by a discussion of the findings. Prior to presenting a brief overview of the process of maternal role formation, the assumptions made by the researcher in analyzing the data will be outlined. A diagrammatic representation of the process of maternal role formation will be presented with the brief overview of the steps of the process. Finally, a detailed description of the steps in the process will be presented in the form of verbatim statements taken from the transcripts. The findings from the instrument, Mother-Child Relationship Evaluation will be presented following the descriptive evidence of the process of maternal-role formation.

The five mothers who provided the data that was used to develop the conceptual framework were given the pseudonyms of Sally, Norma, Sandy, Mary and Terry. When necessary, names used by the mothers in their verbatim statements were also changed to protect the identities of these people. Four of the mothers (Sally, Norma, Sandy and Mary) were primary informants in this study, while the fifth mother (Terry) was an informant in another study for which permission was obtained to use the transcripts for secondary analysis in this study. The statements made by the informants provide the evidence to verify the accurate representation of the core categories which illustrate the process of maternal role formation following the birth of an infant with Down Syndrome.

All of the five informants were multiparas with at least one other healthy child. For the purposes of this study, the researcher assumed that each of these women had personal knowledge of motherhood and experience with motherhood as a result of their being the mother of other children. In addition, it was assumed that each of these mothers had experienced the formation of attachment relationships with her previous children.

None of these women had a family history which would indicate the possibility of having a child with Down Syndrome. Each of the women described their pregnancies as normal and none of them experienced anything in their pregnancy which would suggest to them or their doctors that a genetic abnormality was present in the fetus. It was assumed that the process of maternal-infant attachment began during the normal pregnancies experienced by these women. The desire to continue the attachment relationship with their expected child was a driving force in the process of maternal role formation in the postpartum period. The major differences between the expected child and the actual child contributed to the difficulties in the maternal role formation. An assumption is made that the formation of the maternal role is ongoing and continues to develop as the mother grows in confidence and competence while meeting the needs of the child throughout the child's life.

While each of these mothers' experiences were unique, commonalities were found which led to the discovery of the process of maternal role formation following the birth of an infant with Down Syndrome. The direction of the steps taken in the formation of the maternal role was fairly consistent in the experiences of the four primary informants. The variation in the amount of time spent in each of the steps of the process was a result of differences between the mother's experiences. As evidenced in Figure 2, the process of maternal role formation begins with the pregnancy and birth experience and continues on with time as the child matures.



*Events that determined a time frame for the process.

Figure 2

A Process of Maternal Role Formation

Overview of Maternal Role Formation

Each of the four primary informants experienced a normal pregnancy which suggested to them that they would give birth to a normal healthy infant. Their expectations for the maternal role were based on their prior experiences as mothers of at least one other child. In addition, the mother's age influenced the mother's expectations for a healthy child. The two mothers with advanced maternal age were aware of their increased chance of a genetic abnormality in the infant but like the other mothers did not think that it would actually happen to them. All of the mothers had heard about Down Syndrome but Sandy was the only mother with personal experience involving children with Down Syndrome.

The birth of the infant initiated the process of maternal role formation. The mothers' expectations of her role in the birth and the infants' status were affected by her previous childbirth experiences and her ability to recognize abnormalities at the time of the birth. Both the gender of the infant and the infant's health status influenced the mother's relationship with the newborn. Both Sandy and Norma were separated from their infant following the birth. These two mothers found this separation as a hindrance in beginning the attachment process with their infant.

The next major step in the process of maternal role formation related to the mother's reaction to the diagnosis. The time at which the mother was informed of the diagnosis of Down Syndrome and the way in which she was told had an effect on the mother's reaction and her ability to relate to the infant. The mothers' perceptions of the care received from health professionals was associated with finding the strength to accept the diagnosis and become involved in mothering the infant. Simultaneously the mothers' involvement in taking care of the infant was associated with her acceptance of the infant.

The responses by family, friends and others in the form of support or non-support became important factors influencing the mother's willingness to establish a relationship with the infant. Acceptance of the diagnosis and positive feelings toward the infant were important factors in determining the mothers readiness to inform others about the diagnosis of Down Syndrome.

All of the mother's found that the return home with the infant marked a major change in their ability to mother the child. The mothers now had control over the care of the infant and were able to establish some sense of normalcy in the home environment. Being at home helped the mothers to focus on the normality of the infants rather than on the child's abnormalities. Indeed throughout the process of maternal role formation the mothers frequently questioned the presence of an abnormality in their infant. The mothers often compared the infants with other children to promote the normality of the infant.

The integration of the infant into the family was associated with the mothers feeling more confident and competent in the maternal role. At this step in the process of maternal role formation, all of the mothers found it important to focus on the present rather than worrying about the future. Upon completion of the interviews, it was evident that the mothers would adapt their role so as to meet the ongoing needs of their handicapped child within the context of the home, family and community.

Prebirth Expectations for Motherhood

All of the mothers experienced what they thought was a normal pregnancy which indicated to them a normal baby. Although the mothers had heard of Down Syndrome, none of them thought that it would happen to them with this pregnancy. The amount of prior knowledge and personal experience with Down Syndrome varied for each woman. However the amount and type of knowledge did not influence the mothers expectations for a normal baby.

Pregnancy

It is commonly accepted that most pregnant women begin to develop a relationship with their unborn infant. The mothers in this study tried to develop a sense of knowing something about their unborn infant by evaluating their own health during the pregnancy. Each of the study informants experienced what they thought was a normal healthy pregnancy suggesting to them that their infants would be normal and healthy. Sally described her pregnancy as normal and her expectation for a normal baby. Sally:

> I was expecting a normal baby. 'Cause my pregnancy was really good...I didn't even gain that much weight, I only gained 17 pounds, which was nice. But I was never sick with morning sickness, I felt really good when I was pregnant.

After the birth, Sally recalls that her husband was upset that an amniocentesis was not done but her response was:

> Like the doctor said, there was no history of it in the family, there was nothing wrong with the pregnancy.

Norma's healthy lifestyle during the pregnancy suggested to her that she would have a healthy baby.

Norma:

> I had a really good pregnancy, and I didn't do anything, you know, I drank very little and I didn't smoke, you know, I exercised and that kind of thing.

Sandy's healthy pregnancy gave her no indication that anything was wrong with the baby. Sandy:

> Nothing, I had an absolutely wonderful pregnancy. I was healthy. We did everything, swimming. And my size was about the same and my weight. So we, and I don't think either of the doctors ever suspected anything....I never thought about it once because I had such a healthy pregnancy.

Mary was living common-law with the father of the child, when she found out she was pregnant. Her initial response was:

> ...to tell you the truth, we I had considered terminating before uh when I found out I was pregnant. Just for the sake that I've already had three kids and I really didn't know whether I wanted another one or not. And it had nothing to do with the fear of anything that would be found.

Mary's healthy pregnancy gave her no indication of any problem:

> Nothing was wrong with my pregnancy, everything was perfectly normal. Nothing gave me any reason that anything was wrong, nothing at all.

Mary's feelings about the pregnancy changed as her boyfriend became excited about becoming a father for the first time:

> So, but after we had decided to go ahead with it, yeah, then we were excited. And it was fun for me because he was just like a little kid with this whole thing. His first and only. And

> uh, he was just fascinated. It's kind of what made it for me because it, everything was so exciting and new for him.

Prior Knowledge

All of the mothers had heard of Down Syndrome prior to the birth of their child but none of the mothers thought that they would have a child with Down Syndrome. Sally had the least knowledge about the disorder and seemed to be the least prepared for the possibility of it happening to her. When asked if she had heard about the condition prior to the birth, Sally responded:

> Just very casual. I just never paid any attention. In fact there was a show on TV a couple of weeks before she was born, on Down Syndrome...My mom phoned and told me about the show and I wouldn't watch it. I said to her that I wasn't going to watch it and she said, "Why?" and I said "Cause, I don't want to know about it."

Retrospectively Sally was annoyed that she had not watched the show but at the time of the show she thought it would never happen to her. Sally:

> No, you always think there's nothing going to be wrong with your baby, it'll be born normal. You don't want to think the opposite. Now, I could kick myself now for not watching it.

Norma was aware that Down Syndrome was associated with advanced maternal age and she felt that if she had been older, she might have been more prepared for the handicap.

Nancy:

> I think if you were older, then you would it expect it more.

Both Sandy and Mary were over 35 years of age during the pregnancy and were aware of the increased risk of having a handicapped child with advanced maternal age. Mary thought about the possibility during the pregnancy:

> I think I was a little bit leery, or apprehensive all through my pregnancy. Simply because, nothing was ever wrong, I never felt any different, but just because of my age, I think.

Sandy felt prepared for the possibility of having a handicapped child with her first child which was born two years earlier when she was 35 years of age. However she was not prepared this time:

> And with her I never thought about it once because I had such a healthy pregnancy and when she was Down Syndrome, that was the shock because I thought we talked about this so much and I was so prepared last time not this time.

Although they knew that prenatal diagnosis was available to them, neither of them had an amniocentesis. Mary chose not to have the test for financial reasons but Sandy's reason for not having prenatal diagnosis was:

> We wanted a family. And we just discussed that we were going to have the children we get. We think we can take care of them (laugh)...we discussed that and we thought well if we get a special child, we think we have got enough love to give to a special child too.

Norma was the most educated of the mothers and had the most prior knowledge about Down Syndrome. Norma:

> At least we knew, you know, had enough knowledge, we knew what Down Syndrome was. And when they said that she had Trisomy 21...we understand that. I have graduate work in special ed. so it's, it wasn't like it was a
>
> total shock. Like we both know about chromosomes.

Both Sandy and Mary had some personal experience with handicapped children when they were younger. Sandy had some personal experience with children with Down Syndrome when she was a child growing up near an educational institution which housed mentally retarded children. Sandy:

> ...we always knew kids who had Down Syndrome and we knew they were different but they still played baseball so who cares. And um I always wondered about their capabilities. I always felt they were untapped. And of course we are talking about twenty-five years ago now.

Mary had heard about Down Syndrome but had little specific knowledge about the condition. She too had some childhood experiences with handicapped children which she felt helped her deal with having a handicapped child. Mary:

> ...the cerebral palsy telethon. And my father used to run this thing when he was alive. And I used to go with him, along with him to several classes, just to go with him....I feel that I've kind of been around the handicapped kids, even though that's going a way, way back in my life time.

Initiation of Maternal Role Formation

The process of maternal role formation was initiated by the birth of the infants. The newborn characteristics, including gender and health status had an effect on the immediate maternal-infant attachment process. At the time of the birth, the study mothers' previous maternal experiences tended to help the mothers feel ready to cope with their new maternal role. While their past experiences did not prepare them for the birth of an infant with Down Syndrome, all of the study mothers felt more able to cope with the handicap because of their prior maternal experience.

Comparison of Present to Past Birth Experiences

All of the mothers had experienced vaginal deliveries with their other children. Each of the current pregnancies resulted in the vaginal birth of an infant with Down Syndrome. The maternal role was initiated by the onset of labour, when the mothers began to experience the pain of childbirth and remember their past childbirth experiences. Mary's labour was induced and she recalls her thoughts at the time that labour began:

> And uh it did start to get me into labour at about three o'clock in the morning but it lasted for about an hour, just enough so that it was a reminder of what that horrible pain is like. And then I went back to sleep.

It was common for the mothers to compare the current birth with their past childbirth experiences. Two of the mothers had uneventful labour and deliveries which they described as easier than their first.

Norma:

> It was a very easy delivery, no stitches. I was about four hours from start to finish, we didn't think we would make it to the hospital. It was very, very fast. The total opposite of my first and uh I was fine afterwards....

Sally:

> For her, it was actually better...Once I went into hard labour, it was maybe an hour, and two pushes and she was out. I was really amazed. 'Cause I was expecting a long time, like how I had with my son.

Sandy's pregnancy ended three weeks early when she experienced premature labour which resulted in a small baby weighing 4 pounds 14 ounces. This was very different from her older child who was born at term weighing 8 pounds 14 ounces.

> And of course I didn't know what a premature baby was like, like a little baby. And so I was kind of getting that mixed up with the Down Syndrome too. ...'cause I was thinking of a nine pound baby versus a five pound.

Mary's current delivery was different from her other deliveries because of her decision to be induced and have a saddleblock to relieve the severe back pain she was experiencing during the pregnancy. However she felt that her previous experience helped her to cope with the delivery.

It was common for the mothers to compare the current birth with their past childbirth experiences. Two of the mothers had uneventful labour and deliveries which they described as easier than their first.

Norma:

> It was a very easy delivery, no stitches. I was about four hours from start to finish, we didn't think we would make it to the hospital. It was very, very fast. The total opposite of my first and uh I was fine afterwards....

Sally:

> For her, it was actually better...Once I went into hard labour, it was maybe an hour, and two pushes and she was out. I was really amazed. 'Cause I was expecting a long time, like how I had with my son.

Sandy's pregnancy ended three weeks early when she experienced premature labour which resulted in a small baby weighing 4 pounds 14 ounces. This was very different from her older child who was born at term weighing 8 pounds 14 ounces.

> And of course I didn't know what a premature baby was like, like a little baby. And so I was kind of getting that mixed up with the Down Syndrome too. ...'cause I was thinking of a nine pound baby versus a five pound.

Mary's current delivery was different from her other deliveries because of her decision to be induced and have a saddleblock to relieve the severe back pain she was experiencing during the pregnancy. However she felt that her previous experience helped her to cope with the delivery.

Mary:

> Well, if I didn't know what I was doing it would have made it a whole lot worse. You know, so I look at it that way too.

Infant's Gender

It was common for the expectant mothers to desire an infant with a particular gender. Each of the mothers in this study gave birth to an infant having the desired gender. As noted by Rubin (1977), disappointments related to a desired gender take time to overcome and may "delay or limit" the attachment process. Having an infant with the desired gender may have helped the mothers to attach to the infants. Mary the only mother to give birth to a boy summarized her feelings upon learning she had a boy:

> And so I guess when John was born, number one we wanted a boy very bad because Ted is the only boy, he comes from a family of five sisters and he's the only son. And I was the only one that could have given him a boy to carry on the name. Okay. So then we were thrilled about the fact that he was a boy and uh that was number one.

Three of the mothers said that they did not think that it mattered whether it was a boy or girl as long as it was healthy. Sandy seemed surprised at how pleased she was to learn that it was a girl:

> When she was born I gave it all away. I always said that I didn't care if it was a boy or a girl and I still don't. I mean I'm still glad we have a boy, I'd love a boy. But uh, when she was born I said to my husband, I mean I always said I don't care if it is a boy or a girl, "I got my girl hon". I was excited that she was a

> girl but I was devastated that she should have Down Syndrome....

Sally admitted that she was hoping for a girl during the pregnancy even though she would tell people that the baby's gender didn't matter:

> So I was really looking forward to having a girl so that I could dress her up and all the things that you want for your daughter.

After the birth of their daughter, Sally's reaction surprised her husband. Sally:

> In fact, right after she was born, I held her. And my husband was amazed 'cause she was still covered with blood and I just grabbed her 'cause I was so happy it was a little girl.

When Sally was asked if the ordeal of giving birth to an infant with Down Syndrome was made easier by the fact that the baby was her desired girl, she responded:

> No, I think if she would have been a boy it would have been the same. To me that really didn't matter if it was a girl or a boy, 'cause I would have still loved it just the same. I just kept saying if only when it was born it was born healthy. No. No, just I'm glad she's a girl so I can dress her up in pink.

Newborn Health Status

The infant's health following the birth was another factor which seemed to influence the mother's ease in attaching to the baby. Mary's baby had no health problems and the Down Syndrome was not evident immediately following birth. However because of her age, she was concerned and asked that the baby be checked for any abnormalities. Mary:

> ...course right away they checked for the normal things that Down's babies would have, the heart uh murmur and all this and that and he doesn't have any of that. He doesn't have any health problems.

Mary said that having a baby with Down Syndrome did not phase her partly because as an infant he was no different to raise than her other babies:

> Um, I would have had more concern of course, if there had been physical problems, especially with the heart.

Two of the study mothers had babies that were diagnosed with heart defects. Sally was scared about having a baby with a heart problem:

> ...the doctors came from cardiology. I was amazed at what they said 'cause when they came in they said she had a hole in her heart. They said "Don't worry she's not going to die on the spot." I looked at them and that really scared me. And I thought, "Okay, that was the furthest thing from my mind", but I guess for them, they had to say, you know, they have to say it that way, to make you feel better. But that was the only thing that, uh, scared me was when they came and said that she wouldn't die on the spot and for a couple of days after it bothered me, 'cause I thought, "Could she?"" You know, is there really a problem in that, but then after they told me that it was not really that major and I wouldn't have to really worry about it.

Sally was told that heart surgery would not be required until the baby was about two years old and that no other problems were present. Sally began to feel good about the infant's immediate good health.

Sally:

> Yeah, it probably is a lot harder for somebody who has had a lot of problems right from the day when they came out of the hospital....So you feel lucky after you hear other people's problems, and you think well I have really no problems.

Norma's infant presented at birth with multiple problems related to the heart defects and had to be transferred from the community-based hospital where the infant was born to a community-based hospital with an neonatal intensive care unit (NICU). A few days later the baby again experienced difficulties and was transferred to a university-based NICU. Norma:

> Probably because of the heart condition was one of the reasons she was so small. They wanted to keep her for growth. Then at four days old she went into congestive heart failure twice and at that point they transferred her [to the university-based NICU].

Norma found that the infant's health problems added to the difficulty in adjusting to the situation:

> I think we had accepted the Down Syndrome long before that but it was a different kind of adjustment of course, just having a new baby with health problems.

The need to adjust to the diagnosis of Down Syndrome became secondary to the other more urgent health problems. Norma:

> One extra problem that I have to deal with. I would have to say that probably we are more concerned about the heart at this time because it is more of an immediate problem.

Sandy's premature baby added to her problems in coping with the Down syndrome:

> So I was getting confused with what was Down Syndrome and what was premature....She could suck that wasn't the problem. 'Cause she was tiny and she was falling asleep.

<u>Recognition of Abnormality</u>

Three of the study mothers became aware of the possibility of an abnormality at the time of the birth but none of them thought it would be Down Syndrome. Sandy's premature labour indicated to her that a problem might exist for the infant. However, Sandy thought that the nurse's request to have the baby removed from the case room was due to the baby's size:

> And I guess partly too she was four pounds fourteen ounces. She was little. Yeah, but she was healthy and strong and a good colour and everything so there was no problem there.

Norma also thought that the infant's abnormal appearance was related to her small size:

> ...he suspected that something was wrong right at the point of delivery and the only thing I noticed abnormal at that point is that I had her but I didn't have her for very long, but I did notice, they told me that she was very small, you know they're all wrapped up so much, it's hard to tell much anyhow. I guess she was so small, like my son was big, he was 8 - 7 and he was round and everything. She looked kind of peculiar but I hadn't really noticed much and I guess when the doctor had suspected something he called this pediatrician to have a look and see what he thought.

Sally recalls hearing the doctor voice some concern about the infant but she did not think that it was important at the time. Sally:

> When she was born I can remember the doctor saying something to the nurse about her tongue sticking out, but at that time, I didn't pay much attention. I just thought you know how baby's have so much stuff in their throat....

Although Mary could see no problems with the infant at the time of the birth she was concerned about the baby because of her age. Mary:

> And then I, I don't know, I just when he was born and they give him to you right away and I just [subconsciously] I just checked, physically wise I could see nothing and uh it was basically because of my age that I was a little bit leery. ...The two doctors that I had deliver John uh didn't seem to feel that there was any cause for worry...no, they didn't. Then I had, I didn't have, I guess once they started getting my feelings and stuff, they went ahead and had the genetics people test him....

<u>Being an Experienced Mother</u>

All of the mothers found that their prior experience with motherhood helped them to cope with having an infant with Down Syndrome. Mary:

> And I don't know, I feel a little bit fortunate because I've got three other children. And I've had the experience of that. Umm, now if this would have been my first baby even though he doesn't have the physical problems that make it any different to raise this baby from any other baby, I think it still would have bothered me because it would have been new for me. But being an experienced mother, if you want to put it that way, um it doesn't phase me in the least. It really, really doesn't.

Norma:

> I'm glad she wasn't my first. You have some sort of an idea of how to take care of a baby. You know, no matter how much you know, you know yourself, when a new baby comes home it's still a stressful time. So I am kind of glad that she wasn't my first, to have all the problems that she does. I think I probably might have had a harder time coping.

Although Sandy found her prior experience as a mother to be helpful, she also found it to be a hindrance. Sandy had difficulty getting her infant to breastfeed which was very different from her first child:

> ...I wasn't a first time mom so I think they [the nurses] sort of figured I knew what I was doing but I never dealt with a preemie baby. I mean 8 pounds 14 ounces, I mean I nursed him on the table and away we went, that was it.

Maternal Reaction to Diagnosis

This step in the process of maternal role formation is unique to mothers who learn that their apparently normal newborn has Down Syndrome. Each of the mothers in the study needed time to physically recover from the labour and delivery in order to cope with the information about Down Syndrome. The way in which the mothers were informed of the infant's condition and the support they received at the time of telling affected the mother's initial reaction to the diagnosis.

Recovery from Labour and Delivery

Each of the mothers had the opportunity to hold their infant after the delivery. All of the infants were in stable condition immediately following the birth, including the two infants with small birth weights. Therefore each of the mothers left the case room relieved that the labour and delivery was over and pleased that their infant was born safely. Mary:

> ...the minute John was born I was crying because it was such a relief. And because it was boy I was just so thrilled, that's just the way I respond sometimes, I cry.

Sandy:

> She was born and we saw her and I held her, like she was on my tummy...I held the baby and then she just said "Have them take the baby out. I need somebody to take care of the baby". She didn't overreact or anything, she knew already that the baby had Down Syndrome. And um then, I had an intern too so the doctor and the intern were stitching my up. And after that we kept asking "Where was Miranda". And the doctor said "I'm just going to see your baby and then I will come back."

Because Sandy was concerned about being separated from the baby, the doctor returned after seeing the baby and told them about the Down Syndrome. Sandy was still in the recovery room with her spouse when they were informed of the diagnosis. This mother was glad to be told right away. Sandy:

> Um, well the way we were told was the best, for us, being told right away.

All of the study mothers, except for Sandy went to their postpartum rooms where they spent some time with their spouse. In each of these cases the fathers left the hospital for a few hours at which time the mothers were able to get some rest. Norma was the only mother who did not feel ready to be told about the diagnosis. She describes her experience:

> A doctor. A stranger actually. She was born about quarter after four and about seven the next morning, a gentleman, I was half asleep said "Hello, I'm doctor so and so, I've been called in to look at your daughter because of these things" and then walked out...This was a two minute deal and then left.

Norma thought she should have been allowed to complete her sleep before being informed of the diagnosis. Norma:

> I mean it's not easy ever to find out things like that but I think there's better ways than others to tell someone. I don't know. Not to wake me up with the news that's for sure.

All of the mothers, except for Norma stayed in the hospital between five to seven days. Since Norma's infant was transferred to another hospital, Norma requested to be discharged home within twenty-four hours. Norma:

> Overnight. She was born Thursday and I came home Friday morning. I would have come home Thursday night if they had let me. It was a very easy delivery, no stitches. I was about four hours from start to finish. We didn't think we would make it to the hospital. You don't want to sit on a maternity ward when your baby's not there and you're feeling blue anyway.

Although it was an easy delivery, Norma still needed time to recover from the multiple changes which occur in the mother after birth. Norma found herself unable to visit the baby in that first twenty-four hour period. Norma:

> They wanted, they told me they would give me a day pass the day she was born, the Thursday right after they transferred her but I just couldn't at that point. I was too tired and too weak and too everything else to go at that point. I needed to get myself together before I did that.

Even after discharge, she had little time for recovery as she went home to care for her two year old, manage her home and find the time and energy to visit the new infant which was in the NICU of a hospital thirty minutes from her home. Norma's difficult time with recovery may have added to her negative reactions to becoming the mother of a sick infant with Down Syndrome.

Being Informed

Two of the mothers, Mary and Norma were alone after their husbands had left the hospital when informed of the diagnosis. Mary did not mind that her spouse was not present as she thought that it was important to know the diagnosis as soon as possible:

> I wanted to know the sooner the better, um it really didn't even occur to me to have Ted there. It wouldn't have made that much difference. I just wanted to know. 'Cause something like that, well the first thing that any mother says is "Is he alright?" And you know if you have any kind of doubt in your mind

> whatsoever, the sooner the better. So that's really the case. Whether Ted was there or not it didn't make any difference to me.

Norma would have liked her husband present for support:

> Yes, just for support and I think it would have been easier on him too. Rather than having to come home and start his [phone calls to tell people about the birth]...and then having to turn around and come back [to the hospital] and that type of thing.

Both of these mothers had never met the physician who came in to talk to them about the baby's condition. Mary:

> I really couldn't tell you what his name was...and uh it was about an hour before Ted and his family came in to see me that night, that first night and um just the way that he [the doctor] was so unfeeling that didn't help at all.

Both Mary and Norma would have preferred to have been informed by a familiar physician. Norma:

> Yeah, it wasn't my family doctor. Probably, or I think that I would have preferred that he was at least there.

In addition, Norma though that the doctor should be willing to spend some time with the parents when informing them about Down Syndrome. Norma:

> I think from the doctor, I mean, was fine but I think that they should be willing to spend time with the mother...I think they need to spend more time in bedside manner, than just the clinical facts.

Norma felt that her experience of being told about her infant's handicap was negative and hindered her ability to adjust to the situation. Norma:

> I think it makes a big difference in adjusting at the beginning, how you're told. I've talked to other people who have said the same thing. You know, I think a lot of the support groups have gone out to start to talk to medical students, and I think that's really important. I mean it's not easy ever to find out things like that but I think there's better ways than others to tell someone.

The other two mothers were told with their spouses present. Sally's physician waited to inform her about the diagnosis until her husband had returned to the hospital. Sally was pleased that her spouse was present and she was satisfied with the way they were told:

> I was glad the way I was told. They weren't mean or nasty, they were very polite and explanatory. It was nice.

Sandy had recently moved to the city so was told by a general practitioner that had only seen her a few times prior to the delivery. She was told about the diagnosis while in the recovery room with her husband. Sandy:

> But anyway, he went and he came back after he had seen the baby. He said "She's okay but there is a problem" and he said "She has Down Syndrome". Just like that, like he didn't hold back from us at all....this doctor and he stayed and talked to us, like he wasn't going to just take that as carte blanche.

Sandy felt that the way she and her husband had been told as a couple was best for them.

Sandy:

> No, I was very happy we were both together. Then I think we both, we both really, you know we talked so much together that we really did accept it. Like we knew it was a possibility so we just said, "you know". But if I had been alone, I had, had to have somebody to talk to.

She and her husband had positive feelings toward the baby even after the diagnosis was told to them.

Sandy:

> And we both, like we just both looked at her and "Gee, she looks pretty good to us." And she's just so cute, and we just, so she has Down Syndrome, we're not turning her in. No, no we're not sending back this version.

All of the mothers, except for Mary preferred to have their spouse present when told of the infant's condition. Mary's situation was different as she had a concern about the baby's health status and requested an examination by a pediatrician. Therefore it was appropriate for her to be informed of the diagnosis as soon as possible whether or not her spouse was present. The experiences of these mothers suggest that the manner in which they were informed about the infant's handicap and the time at which they were informed can influence the mothers initial feelings of attachment to the infant.

Initial Reaction

The most common reactions experienced by the mothers were shock, denial and grief. Other initial reactions that were identified were fear, disappointment and shame. All of the mothers except for Mary experienced shock as their initial reaction to the diagnosis. Sandy:

> I think it's a shock. Like I definitely went through shock, I know that.

Norma:

> I think if you were older, then you would expect it more. The shock. Total unacceptance in the beginning.

Sally was the only mother that said she was scared when she was told that the baby had Down Syndrome. Mary said that she did not experience shock because the diagnosis was a confirmation of what she had thought possible due to her age. Mary:

> ...like I said, that had always been in the back of my mind that that would be a possibility.

Both Norma and Sandy discussed the denial that they experienced after hearing the diagnosis. Sandy:

> And I know I went through denial, 'cause she seems so normal that I just am going, I can't believe that this can, I mean you tell me, so intellectually I believe it but emotionally I think I, I know I denied it until he finally phoned with the results and told us.

Norma:

> You go through a whole cycle of things. Denial, it's not there. Why me?

All of the mothers experienced an initial sense of guilt for different reasons. Mary thought it was her fault because of her age.

Mary:

> I was upset for twenty four hours 'cause I went through a thing of baby blues, plus I went through a thing of thinking that it was my fault 'cause of my age, you know, I went through that thought.

Sally:

> Yeah, in the beginning. What I had done wrong. Yeah and why did I wait so long. Maybe if I wouldn't have waited so long to have her, maybe this wouldn't have happened. All those type of things run through my head.

Sandy:

> Yeah, well I wondered if it was something that had caused my eggs to be damaged or something along the way.

All of the mothers said that they cried a lot for at least the first twenty-four hours. The study mothers described this emotional state as being upset or bothered by the diagnosis. Mary:

> ...um I was upset with myself in the beginning, at the very beginning, like in the hospital...I was upset for twenty four hours....so I was crying, or getting over crying. I was sort of in spurts off and on...

Norma:

> At first I was upset and tired....I cried much more than he [her husband] did which is natural.

Sally said that she was bothered by the diagnosis for about two weeks. After that time she experienced disappointment:

> Disappointed. I waited so long for her 'cause my older boy will be ten in the spring.

Norma was the only mother to discuss the negative thoughts that she had during the first week after the birth:

> So you would go through a period of feeling well maybe we're, maybe she would be better off, it would spare everybody the long term kind of thing. And then you would feel guilty because you felt that way at the beginning and then you would think "Oh my god this is my baby and I wish it was dead" kind of thing and she's not. So you go through a real realm of real nasty, real ugly thoughts for a while. That lasts for the first week, you know, you're just a real roller coaster...that's the time that's the hardest. When you're mind is stuck with all these negative things, I mean, no mother wants to have these thoughts about her own kid.

A preoccupation with the diagnosis made it difficult for the mothers to initially get to know the baby. When reflecting back on this initial period of time, Norma recalls how her thoughts were always on Down Syndrome:

> I think that when the news is new, it's a 24 hours a day, sixty minutes an hour, that you think about it. It's just your entire life revolves around Down's, basically, especially when she was still in the hospital, the first two or three weeks anyhow. That's all you think about. You wake up in the middle of the night and that's all you think about.

Mary said that she was initially self-conscious about having a baby with Down Syndrome. She dealt with it by taking the baby with her everywhere in the hospital. Mary:

> As time went on I was there and John was with me and I would take him into where we had meals and all this and that. Uh, nobody, nobody noticed it...and it just made me feel, I felt a little bit [self-conscious] for awhile. You know, and uh, uh I really did quickly get over that.

Of all the study mothers, Sandy's initial feelings of attachment to the infant seemed the least affected by the diagnosis. However, she too recalls how she spent the first night crying as she worried about how she would care for the baby and the child's future:

> So they gave me something and I probably slept for two or three hours and then I woke up and I reconciled the first of my tears and then slept. But of course I was bawling and everything 'cause I was kind of upset and you have to determine if she is going to be married, and going to have kids and how she is going to take care of herself when she is eighty. And I had to get this all figured out in my mind and uh I was crying and that and the nurse came in and she said "You've got red cheeks" and I said "Well I've been bawling".

Summary

The initial reactions experienced by these mothers dampened their desire to take on the maternal role and influenced the mothers attachment to the infant. Both Mary and Sandy seemed able to get over their initial grief sooner than Sally or Norma. Mary said that she was upset in the beginning for about twenty four hours while Sandy was eager to be with the infant and begin breastfeeding immediately. Both Sally and Norma said that it took at least one to two weeks before they were not "bothered" by the diagnosis. However, all of the mothers continued to experience a sense of loss related to having a child with Down Syndrome rather than a normal child. Mary and Sandy were the two mothers with advanced maternal age and were more prepared for the possibility of their child having a handicap. In addition, these two mothers had personal experiences with handicapped children when they were younger, which they both described as positively affecting their attitude towards the handicapped.

Maternal Acceptance

In addition to the physical recovery from the labour and deliver, the mothers required a certain amount of emotional energy to assist them in accepting the diagnosis and continue in the process of maternal role formation. While the infant was in the hospital, supportive health professionals assisted the mothers to find the necessary inner strength for acceptance. In addition, the mothers gained strength from their spouse and spiritual beliefs. As the mothers became more involved in caring for the baby, they simultaneously became more accepting. Their feelings of attachment for the baby became stronger with the developing maternal role.

Finding Strength

The feelings of responsibility for the infant's condition made it difficult for the mothers to feel good about being the mother of an infant with Down Syndrome. All of the mothers said that the guilt was relieved by gaining more knowledge about Down Syndrome. Sally:

> No, because with what the doctor told me and that it made me feel a lot better knowing that it was not anything that I did. But up until when he [the medical geneticist] explained everything then you get kind of weird feelings that maybe if I had done this or done that but he said there is no way no matter what you do or did, it didn't cause her like that....

Norma:

> So umm I suppose there was some concern at the beginning thinking now what have I done that caused this but...not a great deal...I would say probably initially for the first couple of days. I suppose even a little more than that, up until when we sat down and had a really good talk with the doctor.

Mary:

> No I don't feel responsible particularly after the doctors and the nurses made it very clear to me that it's happening more and more and more with younger women.

Sandy:

> Yeah, well I just wondered if it was something that had caused my eggs to be damaged or something along the way. But yeah, that was the only thing I went through but it was just made so clear to us so many times.

Gaining knowledge from health professionals helped the mothers get to know about the Down Syndrome and feel more comfortable in being with the baby. Mary:

> I asked a lot of questions. I think I bothered everybody in fact I asked so many questions. I spent most of the time in the nursery....They did the best that they could. The only thing is that it was too much too fast to absorb and um that's why this lady from genetics she was a big help to me. She talked slow, she'd repeat things, she came back maybe the next day and

> repeat what she told me the day before....um then I spent a lot of time with him [the baby]....

Sally:

> Because for them it's their medical terminology and they just rattle on and expect you to understand what they are saying, but I have to say that the doctors at the hospital were very good and the nurses, they really, they helped me a lot.

The mothers felt stronger about being able to cope with a handicapped infant when they perceived that a health professional was supportive. Initially Mary felt badly about not having had the amniocentesis to determine if the baby was normal. However her doctor talked to her after the birth and his support relieved her guilt and made her think about the positive side of having gone through with the pregnancy. Mary:

> He came into the room and he told me "Don't even think about it twice because" he says if him and his wife had had a child, yes they did have a child. He said "If we would have been able to find out that this was going to happen. Are you going to make the decision that you are going to terminate it?" And he said "Especially as much as you wanted a boy." And uh so he says "In a way, this way you weren't comported with a decision to make (sic)." Which is true, I mean, he was trying to give me other alternatives, you know make me think differently....and so, my doctor was very, very helpful to me and it really made all the difference in the world. He really did.

This same mother received support from a few other professionals in the hospital.

Mary:

> And the lady that I became friends with that did my ultrasounds all the time, she was a big help to me also. And um reassuring and so were a couple of the nurses that were in the nursery.

Terry said that the support from the hospital staff helped her to realize that her experience of having a baby with Down Syndrome was not a bad thing. Terry:

> Well, I have to say the whole staff there at the hospital, umm was so supportive it was just like I had gone to heaven for awhile, and 'cause everybody was just so, [so good] when I read stories of other peoples experiences that were so bad, you know when they discovered their baby had this problem but, like I couldn't think it was a bad thing that had happened to you because so many people were so great.

Norma and Sally had the opportunity to speak with a nurse at the hospital who had a child with Down Syndrome. Both of these mothers gained a more realistic image of Down Syndrome which helped to reassure them about being the parent of their infant.

Norma:

> What really helped us is there is a nurse at the hospital that has a daughter that is nine...umm, that has a daughter with Down Syndrome, and the second day she was working and my mom and I were there and she came over and stopped and said that she "would like to talk to you about my daughter". And brought us a picture and we sat and I bet she sat and talked to us for at least two hours, more than that. And I think that that was kind of the turning point for me, she had been in, she was about three days old.

Sally:

> But it was really nice in the hospital, there was, one of the nurses has a Down Syndrome boy which was older and she came to talk to me and

> show me pictures of him which made me feel much better.

Sandy awoke from her first night's sleep and began to worry about how she should care for the baby. A nurse reassured her that she should care for the baby the same as any other baby. Sandy:

> And anyway she said why was I crying. And I said "Well how do I treat my baby?" And she said "What do you mean?" And I said "Well do I treat her like a normal baby?" And she said "Yes".

This same mother was concerned that her baby might not have the will to live. The nurses reassured Sandy and helped her to feel more secure about the infant's health. Sandy:

> And I thought, I wondered if she had a will to live. So I said that to the nurse. "Of course she's got a will to live. She's just small." ...one of the nurses told me. The ones I was telling you that need the commendation. I was worried she wasn't strong enough to suck, she said "she's strong enough" and of course she was.

Both Norma and Sandy talked about their spouses as a source of support. Norma found that she needed some time alone with her spouse in order to find the strength required to cope with the situation. Norma:

> My mom and dad had come up that night, we were still trying to work through things ourselves and we weren't really ready to work through things with other people.

Two of the mothers felt that their spiritual beliefs helped them to be more accepting of the situation. Mary's spouse was thought to be sterile due to an injury yet Mary learned she was pregnant. She found the strength to accept the birth of a handicapped child by believing in the powers of fate. Mary:

> But that he's, that he really couldn't be accepted any more than what he is right now because I feel that he was born to me for a particular reason somehow.

Sandy believed that the birth of her special child was due to the powers of God. Her spiritual beliefs helped her to accept the responsibility for being the parent of a handicapped child. Sandy:

> And when she was Down Syndrome, that was the shock because I thought we talked about this so much and I was so prepared last time not this time. And I thought there's God, he gets you, he plays tricks on you....Well no, we discussed that and we thought well if we get a special child, we think we have got enough love to give to a special child too.

Involvement in Mothering the Infant

As the mothers gained the emotional energy to face the birth of their infant with Down Syndrome they were able to come to terms with their negative feelings through acceptance. As a part of the process of maternal role formation, accepting was multifaceted. The mothers had to come to accept the diagnosis, the maternal role in caring for the baby and the infant as their own child. Becoming involved with the infant helped the mothers to gain acceptance.

Accepting the diagnosis. Immediately after hearing the diagnosis, all of the mothers except for Sandy withdrew from the baby. These mothers needed time to think about the diagnosis and gain the emotional strength that was required to accept the infant's condition.

Sally:

> I think I maybe would have not believed them if she had been laying there beside me. This way it gave you time to think about it.

Norma did not accept a day pass to see her infant at the hospital where she had been transferred a few hours after birth. Norma:

> I needed to get myself together I (laugh) before I did that.

Sandy's reaction was different from the other mothers as she wanted to see the baby immediately after being informed of the diagnosis. Sandy was upset with being separated from her infant. Sandy:

> We both said "Can we have her" and he kept talking. And we said "Can we have our baby". And finally he brought her to us and that to me was the worst trauma I had to go through was not to be able to have my baby....He came right back and let us be with her and we took some pictures and everything.

Sandy's reaction may have been different because she did not believe that the baby had Down Syndrome as the baby seemed so normal. She said she did not fully accept the diagnosis until the chromosome results came back positive for Trisomy 21.

Sandy:

> Well sure and uh I knew, like I knew she was Down Syndrome, I knew 'cause I knew to look at her. But by the same token, when I was just watching her I thought, you know, well, maybe she's pretty normal so when he did actually say it I thought "Well that's good, now we are past that. Get on with it, you know, don't waste any more energy."

<u>Accepting the maternal role</u>. After initially being apart from their infants, the mothers wanted to spend time with the babies so that they could get to know them. Mary:

> You got to get to know the baby. And you, know, of course when they are an infant there is everyday something different.

Mary got to know the baby by keeping the baby with her all day while she was in the hospital. Mary:

> I didn't breastfeed so um what I did was he stayed with me all day long up until about 10 o'clock and then I put him back in the nursery so that the nurses could watch him....As time went on I was there and John was with me and I would take him into where we had meals and all this and that.

Norma said that she had to work on bonding with the baby by going up to the hospital every day to see the baby in the NICU. Norma:

> ...we took turns going up, we were there everyday pretty well, at least once, usually two or three times...

When Norma was asked what helped her to get to know the baby she said:

> Nothing in particular, I don't think. Like I can't think of a certain event, or you know, I

> suppose it is just a natural mother-infant bonding.

Some health professionals helped the mothers to be with their infants. One of the nurses helped Sandy to be comfortable in being with the baby and caring for her. Sandy:

> And I said "Well can I hold her?" And she said "You can hold your baby" and she took me to the nursery. And after that as soon as I knew where the nursery was that was where I lived.

Two of the mothers wanted to breastfeed their infants but were confused by the mixed messages they received from the alternating nursing shifts. Sandy:

> It was really weird because one shift they were encouraging you to nurse her and the next shift they were encouraging you to bottle feed her and they just wanted to get you out of the hospital, anything to get her gaining weight, right.

Terry did not begin to breastfeed until the fourth or fifth day because the nurses were bottle feeding or gavage feeding the infant. Terry was pleased with the support she received from some of the nurses and recalls the nurse who encouraged her to breastfeed:

> When Mrs. Smith comes on you get her to help you with the breastfeeding. And she is just great. Tips and I think her motivation is and just her personal attention and she came all the way down to get me when it was convenient for her all the way down from another floor, and she would sit me down and just say well, you've got lots of milk there and here we will get the baby on, and take in the baby's mouth and how to get it open and get the nipple in it, and just saying we have another kind of pump here that you can use, and it was so much better than those horrible bulb ones....She's really a high point.

Sandy remembers a nurse who made her feel uncomfortable about her decision to breastfeed her infant:

> I know from one nurse I got the feeling that it was like, and this might have been my perception and it could be wrong like I might have been oversensitive but I got the feeling that she thought you know just feed him, give him a bottle, she's got Down Syndrome what are you worrying about, who cares. As for me, my feeling was all the more reason to do as much as you can for her....

Being able to breastfeed was important to these two mothers as it helped with the maternal-infant attachment process. Sandy describes how important it was for her to breastfeed and her disappointment with the baby initially needing a nipple shield:

> Oh, well I would like to have her nursing, nursing. But I'm certainly satisfied with second best. I just miss the bonding with the one on one. Like I like the feel of nursing. So if I can get her to latch on a couple of times a week, it satisfies my brain a bit.

Terry felt that it was important for her infant's emotional needs to breastfeed but realized that the baby tired more readily when nursing. Terry:

> I think in her little heart she prefers to nurse, but she doesn't get enough out of it.

Norma tried to breastfeed her infant but the baby became tired too easily from the exertion. Instead Norma pumped milk and gave the baby the breast milk with a bottle. When asked if it bothered her that she was unable to breastfeed the infant, Norma replied:

> It didn't bother me. My son nursed for about three months and that was just fine. She had milk for about two and a half months so, they both had about the same.

The hospital environment inhibited the mothers from being involved with the infants. Mary spent most of the time in the nursery for the first few days before the baby was allowed to be with her during the day. When asked if she was encouraged to spend time in the nursery Mary responded:

> No, I mean no they didn't. This was before he was able to come and stay with me most of the time during the day because he was there for a week, I was also six days anyway.

Sandy was not allowed to have the baby in her room. She found the separation from her infant to be a hindrance which she had to overcome in order to get to know the baby. Sandy:

> They tried but I wouldn't let them. Well the first night, it drove me crazy. They wouldn't let me hold her and like it drove me nuts and then finally at 5 o'clock the next morning they showed me where she was and they couldn't get rid of me, they could try and I still looked at her at night and everything. They'd phone me and I'd come running down and feed her. She was never allowed to stay in my room until I got discharged....

As more time was spent with the infants, all of the mothers, except for Norma began to realize that the maternal role in caring for an infant with Down Syndrome was similar to their past experiences with a normal infant. Mary said it took her twenty-four hours to become accustomed to having a baby with Down Syndrome. When asked if she was comfortable in caring for the baby at the beginning Mary said:

> Um, comfortable? The only way that I can answer that is that the Down's part didn't have anything to do with anything. It was just learning how to handle a baby all over again.

It took Norma longer to accept that she would have to be the mother of an infant with Down Syndrome. The NICU environment inhibited Norma from becoming involved in caring for her baby. Norma:

> Well, she was in the hospital six weeks, so... I'd have to say probably a good two or three months. Once we got over the major health difficulties, as long as their in the hospital it's hard to treat them like a normal baby, which is what you're obviously going to strive to do. But when they're all hooked up to this that and everything else....

Accepting the infant as their own. The realization that a baby with Down Syndrome is similar to a normal baby helped the mother's to accept the infant as their own. Sandy:

> Like that's why I say, I accepted her totally right from the beginning but I was probably denying too, just because she seems so normal.

Sally did not spend a lot of time caring for the baby until she went home. It took her about two weeks to accept her handicapped infant. As Sally spent more time with the baby her feelings toward having a baby with Down Syndrome changed.

Sally:

> And then when I came home and I saw her and held her, to me she was no different and it didn't bother me any more.

Initially Norma found it difficult to accept her baby because of the baby's poor health status. Norma:

> Total unacceptance in the beginning. Or at least that's what I found. I went through a period when she was very ill thinking maybe things would be better off if she had just died at that point.

As Norma was able to become involved with the baby she began to dwell less on the problems and more on caring for the baby:

> And then as time goes on you begin to not totally dwell on, on all the problems and you become more involved in just taking care of the new baby. And it settles down.

All of the mothers expressed acceptance of their infant. Norma:

> We wouldn't trade her now, I mean we wish that she wasn't what she was but I mean I wouldn't want a different baby.

Sandy:

> And we both, like we just both looked at her and "Gee, she looks pretty good to us." And she's just so cute, and we just, so she has Down Syndrome, we're not turning her in. No, no we're not sending back this version.

Sally:

> I love it. She's mine. I know I gave birth to her and no matter what you say nobody could take her away from me.

Mary:

> And uh, um I just feel that if John had to be born they way that he was, that he's lucky that he was born to me. Because and then I'm lucky to have him....And um I just feel that it's not going to be a problem between him and I.

Informing Others

Initially the mothers relied upon their spouses and other family members to inform close friends and family as they found it difficult to inform people about the diagnosis. The reactions from the people that were informed affected the mother's attitude towards being the mother of an infant with Down Syndrome which in turn influenced the mothers willingness to inform other people. As the mothers became more accepting, they found it easier to inform other people about the Down Syndrome. Simultaneously, informing others helped mothers to overcome denial and become more accepting.

Receiving Support

In two of the cases, the husbands were not present when the doctors informed the mothers of the babies' abnormality. Both mothers found that informing their spouse was a difficult task which they did not feel prepared to handle. Mary obtained the support of the nurses by making an arrangement with them to inform her spouse of the diagnosis:

> It's just at the time I didn't want to have to tell him, 'cause I didn't think that I would be able to get it out. I was pretty upset at the time. So this is why I made the arrangement with the nurses.

Norma phoned her husband immediately after being told about the diagnosis. When asked if she told him on the phone she said:

> I don't remember. I think I did, but he didn't really, he knew something was seriously wrong because I was bawling on the telephone.

Norma and Sandy relied on their spouses as their major source of support. They found that their husbands accepted the infants immediately. Norma:

> He's been very supportive, he accepted it right from the beginning. There was never a problem. The only thing that happened to daddy was he started to smoke again. He had quit but he started the day she was born.

Sandy:

> Yeah, and he is totally accepting. He hasn't, I don't know if he's, I don't know if he is going to have a total breakdown some time or not but he has been so totally accepting of her. She's his little girl, he hasn't cried and he's quite an emotional person.

Mary and Sally described their spouses as being upset after hearing the diagnosis. However, Mary felt that her husband was supportive as he tried to comfort her:

> So then they all left and came back to the room and he was crying. But he was crying because he knew that I would have blamed myself for this....Yeah, and he was trying to comfort me

> and saying "Hey it's not your fault, it's just one of those things".

Sally's husband provided little immediate emotional support but he too came to accept the baby after she came home:

> He was upset. In fact, he left right after the doctor told us. He left the hospital. And it took him a while to come back. For him, all his dreams were shattered....But he's accepted her now and he understands more about it.

All of the study mothers relied upon their husbands to inform immediate family about the Down Syndrome. Norma's husband had to contact family members twice, once before being informed of the diagnosis and again after hearing of the diagnosis:

> He had come home, actually what had happened is he had come home and made half of his phone calls and then I called him back to tell him the news. He came back right away and then he called everyone back and retells them the news.

One of Sandy's immediate concerns was how her parents would react to the news and how she would handle the situation. Sandy:

> Actually the first night, that was one of the most traumatic things for me. And I guess because I didn't know how they were going to react to us. Especially my mom, mom and dad....How they were going to react to her and how I was going to react to this whole mess in my lap.

Sandy asked her husband to call her mother the night of the birth.

Sandy:

> I said "You've got to phone Mom and tell her because Mom is going to go nuts." Like, well you know what mom's are like and I suppose we would too, I don't know...So he phoned and he said "Sandy had the baby. We have a little girl and she is healthy but she's got Down Syndrome." And my mom said "Okay, goodbye". And he said "You're not getting rid of me that easily". And he made her talk and then he went and spent the night with them and he told them, "Listen this is our baby. We discussed it before she was ever born and we are keeping her and that's it."

All of the mothers said that family members who were told of the baby's condition were supportive and accepting of the baby. Sandy thought that her parent's acceptance was related to the way her spouse had informed them about the baby:

> And my mom and dad came up the next day....and because he had just laid it down on the line and said "This is the way it is". They just came in and they were totally accepting of her.

The parents of two of the mothers came to stay with their daughters after discharge from the hospital. Norma's mother helped out around the house so that Norma could spend more time at the hospital with the baby. Norma:

> My mom and dad came the Friday, the day after she was born and uh they both stayed for three or four days. My mother stayed for two weeks. And she took over the house and basically and my son and that kind of thing so we were free to go back [to the hospital].

Terry was grateful for the help she received from her parents.

Terry:

> Yeah they were both here and that helped, with the four year old, um 'cause she kept grandpa busy....Oh it was wonderful! I probably will never realize how much benefit that really was.

Mary had recently moved to the city and had no friends or family living here. Mary's father was deceased and her mother was very ill at the time of the birth. Mary chose not to inform her mother and a few months later, her mother died having never seen her grandson and not knowing that he had Down Syndrome. However, after her spouse informed his family about the diagnosis, Mary received support from her mother-in-law:

> And so she was very reassuring and she was, kept on saying to me "They are some of the happiest children and they are the most loving children." She did everything that she could to try to reassure me.

After receiving initial support from family members who were informed by their spouses, the mothers began to inform other people. Both Sally and Norma told their other children that the new baby had a problem.

Sally:

> We told him right when she was born that she had a problem, that she was ah, he said that it didn't matter, that he still loved her.

Norma:

> We've told him right from the beginning basically. I don't think he totally understands. He has a book, friends gave it to him.

Norma wanted her son to understand about Down Syndrome as she was concerned about the reactions he might have to face in the future from other children:

> He knows the term retarded, umm, I'd rather he learned it here, 'cause I mean obviously as he grows older and goes out more on his own, he will get his.

Sally found that while she was in the hospital she could not tell anyone, other than her son, about the baby's condition and did not want visitors other than the immediate family. Her mother helped her to tell her friends from work:

> ...so I couldn't, I couldn't even get the courage to phone anybody...In fact, I was really stupid, I could kick myself now for that, but umm the girls from work were going to come up and I told my mom to phone them and tell them I didn't want to see them. And my mom said to me "Well why?" and I said "'Cause I just couldn't face telling them that she was born Down Syndrome".

A support visit from a mother and her five year old child with Down Syndrome reassured Sally about being the mother of an infant with Down Syndrome. After the visit she was able to begin to face her friends from work:

> I phoned her at night time and I said to her that I was going home tomorrow, why didn't she pop over to the house and she said "Oh you want to see us now?" I said "Well I just couldn't talk to anybody, I just didn't know what to say." ...'cause then the day of the, well actually the night that I phoned her was the day that the lady came from Gateway. So which made me feel and realize that, you know, "Don't be so stupid".

After their initial delay, Norma and Sandy started telling everyone about the Down Syndrome. Norma said that telling others helped her to face the situation:

> And as I said I forced myself right from the very beginning to be honest or not to hide it. I decided then that, you know, this is my daughter and I might as well get used to it right from the start.

Sandy felt that telling people about the Down Syndrome helped her to deal with her denial:

> I just started telling people. 'Cause I thought you just have to do it. I didn't want to and I was hurt to say that my baby isn't perfect. You know, we all have that expectation I think. ...So I, I tell people that I know in the hospital, every person I talked with I thought I've got to deal with this. So every single person I saw I told that she has Down Syndrome.

However, after becoming more comfortable with informing people about the baby, Sandy said that she had to use some judgement in deciding who to tell:

> I was from one extreme to another. First of all I just felt I had to tell everybody so, "Excuse me, could I just share this with you?" And I thought listen, whoa back a little, you don't have to tell everybody. So I get talking to someone and if it's one of those baby conversations, where you're just talking and they say "Oh gee, your baby's cute. " I say "Yeah".

Mary said that most of the time she would tell people about the Down Syndrome. However, she tended to inform people after they had gotten to know the baby:

> I did tell one friend that had known John ever since he was about two months of age and she was totally shocked....Then my next door neighbor

> she works with these types of kids. So she says "Oh does he have Down's?" and I said, "Yeah". So but that was after the fourth time that she saw him....It's easier for me to [tell] so I don't have to go around wondering if they're wondering. So I just get it over and done with in most cases.

Sally also preferred to tell people about the baby's condition after they had spent some time with the baby. Sally:

> But I had an experience, I took her to one of the hockey practices there and none of the moms had known that she was Down Syndrome and they said how good she was and that she was holding up her head well. Until afterward, just before I left I told them and they couldn't believe it. So that made me feel good.

All of the mothers said that everyone who was told of the Down Syndrome was supportive and accepting of the baby. However, after telling some people about the Down Syndrome, Sally was uncomfortable with the complements that people gave to her about the baby:

> Sure, 'cause once you tell them it's Down Syndrome, first thing they look at you and they don't know what to say till they think about it for awhile....I don't know in the back of your mind, you wonder are they just saying it to be nice to you. I don't know, like a lot of times I think well they say it real serious but inside are they saying it because they don't want to hurt your feelings?

Norma said that it was not difficult to tell family and friends because of all the support that they received from these people:

> Actually family members and friends have just been fine. We have had no difficulty what so ever with people accepting it.

Coping with Non-Support

It was common for the mothers to say that a person's reactions to the baby were related to the time spent with the baby. Norma was concerned that her husband's parents had not accepted the baby's condition. She felt it was because they lived out of town and were unable to see the baby.

> I'm not sure my husband's mom and dad have completely accepted it. I think at times that dad, my husband's dad has a feeling, that after surgery everything is going to be, just fine but they haven't seen her either.

Sally thought that it took her husband longer to accept the baby because he was working out of town:

> I think it took him a little while longer, especially because he was working out of town. So for him, he wasn't home seeing her all the time. And then when he did come home he realized that she was no different than seeing our son when he was little.

Mary thought that her children from a previous marriage would not accept her new son unless they were able to spend time with him:

> If they could be around John, you know but it's not that way so...and they can't see him for himself, for their self....

Mary's older children live with their father in another country. Mary thought that her ex-husband would be non-supportive and would influence her children 's attitude toward the new baby:

> ...if he [ex-husband] found out he would say something on the order that "Well I knew his father couldn't father a normal child" or something, he would say something very cruel like that. He would and then he would repeat it, almost to the word back to my other three kids. He would not give, he would not explain to them.

Since Mary thought that she would not receive support from these family members she chose not to tell them about the diagnosis of Down Syndrome:

> See that's why when I tell you that I haven't told the other kids or this and that, it's not that I'm afraid to or any other reason, there are particular reasons which now that you know because I don't hesitate to tell other people. But with this particular situation it is different.

In addition, Mary husband's family initially decided not tell the baby's grandfather about the Down syndrome because they thought that he would not be supportive:

> Yeah I was told right away um you know when I got back home from the hospital that Ted's dad didn't know. They didn't um his mom didn't want to tell him....That she feels that he has got this feeling that if he knew whether it be any kind of a handicap not just this, that he would not understand and that he does not accept any kind of person, child or adult with a handicap.

Mary was upset by the decision not to tell the grandfather and was unwilling to keep the Down Syndrome a secret:

> I'm not going to go hiding it 'cause if it is going to be there, it is going to be there. I'm not going to prevent John from thinking or of having the fear that his grandfather doesn't know this. I'll be darned if I'm going to keep

> John away, you know. And if John has difficulty in whatever in the future and it is noticed by the grandfather, I want him to know now instead of wondering why later.

Mary was relieved and pleased when her husband finally told his father about the Down Syndrome:

> And his [the grandfather's] response was um "Well I guess you're just going to have to love him all the more". That's exactly what his response was and I was very pleased with that because he was not given the chance to even give his opinion and that's why I told you it was upsetting me.

Norma was initially uncomfortable taking the baby out where strangers might see her. She described her own reactions to one negative experience she had while taking the infant out to the mall. Norma:

> The first time you go to a mall or that kind of thing. I've never had anyone come up to me and ask me if she has Down Syndrome. We did have some comments, she has eye trouble...but when she was a newborn, they would maybe half close and we have had the comment or I have, at a shop when she was asleep, this old biddy, "Look at that baby she doesn't close her eyes right, isn't that weird?" I thought "That's not all that's wrong with her lady, butt out."

Norma decided that support from others depended on the experience that the people had with Down Syndrome:

> Depends on who you talk to. People in the medical profession are usually fairly optimistic, and the people who work with the Down's kids and especially the people who are involved in the area with programs and those kinds of things, are definitely optimistic. The old school people, no, they're not optimistic. They're umm, like my grandmother and those kinds of people. She went to see a

> lady who had a Down's baby who is my age now and they don't realize that things aren't the same now.

Maternal Role Transition

A major transition in the maternal role occurred when the mother was allowed to take her infant home. The mothers found that they were constantly reminded of the infant's abnormality while in the hospital whereas the home environment helped them to focus on the infants' normality. Taking control of the decisions regarding infant care was evidence of the mother's desire to do the best possible for the child.

Returning Home

Norma had to wait the longest before she was able to bring her infant home from the hospital. Although she was discharged in twenty-four hours her baby stayed in the hospital for six weeks. Norma found that it was difficult to meet both the needs of her son at home and the baby in the hospital. She described how she tried to juggle these responsibilities:

> That's a hard thing, it was hard when she was in the hospital so much because you are trying to keep some sort of a normal situation here for our son's sake and for your own. To keep your household going and those kinds of things and yet you should be at the hospital. And that was difficult, juggling kind of two different things. As soon as she came home it was much better.

Mary best described the feelings of the mothers as they were in the hospital being reminded everyday about the infant's condition:

> Then every single day they were telling me all this information that was so hard to absorb. And telling me all these doctors names, telling me that there is this sort of thing that is offered for you and that sort of thing that is offered. And I couldn't take it all in. It just was made things a little bit harder to, to, not accept, but to deal with. Well everything at that point, makes your head swim. Actually I was wanting to get out of there and just go home.

Mary wanted to go home where her life could be normal again and she would stop being reminded of the abnormality. Mary:

> Yeah, exactly because it really was as long as I stayed there it stayed in my mind more so than when I got home. Not that you want to block it out but everything at that point had been proven negative other than the fact that he did have it.

Sandy was afraid of going home and having to take on too much responsibility. She had recently moved to the city and they had not yet unpacked the boxes in their new home. She describes her experience of going home:

> It was good [going home] but it was totally [disorganized], because we were just in boxes we moved in on the first [of the month], she was born on the third and I was afraid to come home because I just thought how am I going to cope but it was okay...we were a mess but anyway so it was good to get out but it was a little fearful. I thought "Oh my god, how are we going to get a meal in this house and stuff" but we managed.

Focusing on Normality

After the baby came home, each mother was able to focus of the infant's normality. Common phrases were used by the mothers to describe the normalcy of their infant.

No different. Both Mary and Sally described their baby as being no different than a normal baby. Mary:

> ...sometimes you gotta just weigh it out and he knows, he's not any different than any other kid that way.

Sally said that her relationship with the baby was no different than if the baby was normal. She also described the baby's appearance and motor development as "no different":

> No different than if she was normal....No, like I said, I really haven't had to experience any different changes in her, except that as she is growing she is doing things that she should be doing.

Just like any other child. It was common for the mothers to describe their baby as being just like any other baby. Sally:

> She smiles and coos and that, just like a regular baby....To me she's just like anybody else's baby. She's my baby.

Norma:

> But she doesn't cry a lot. I was quite concerned for awhile. But she has a temper too, you know like any other baby.

Although Norma's baby had remained in hospital for six weeks with a number of additional problems, after discharge home, Norma made the decision to treat the baby like a normal infant. Norma decided to take the baby on a trip four days after she was discharged from the hospital:

> And umm we were determined that we weren't going to hold back. I said to the pediatrician "Can I take her away?" and she said "Would you take a normal baby away?" and I said "yes", "Then take her, she's the same as any other kid." And I have to admit we have really done that.

Normal. The mothers often used the word "normal" to describe their baby. Mary found her baby to be like having a normal baby:

> He really is [normal]. He wasn't. I ran into a little bit of colic with him, but that's normal too.

Sandy also saw a similarity between her infant and a normal baby:

> She just strikes me like I said she's so much like a normal baby that you have to remind yourself because you don't want to set yourself up for a big disappointment.

The mothers would often rationalize any differences between their infant's development and other children's development as within a normal developmental range. Mary's infant was almost the same age as her friend's baby who was developmentally ahead of John. Mary would not admit that her infant was slower than the other baby, rather she would say:

> Well like I told you before the girl over here and she's three weeks younger than John and she already pulls herself up to the table, the couch. Oh no, I know she's very early....She's very advanced in her maturing.

Norma recognized a difference in the developmental skills of her two children when comparing them at similar ages. However she tended to describe the older child as a fast developer and saw her infant as within the normal range:

> And the delays just not there yet. You know, I'm not saying that, she's behind where he was but then he was fast so....he's the opposite, he's extremely bright....it's hard not to compare the two because he was running at a year and walked just before he was ten months old. He was, you know he was a real goer. He was very independent and that kind of thing. Whereas she's going to be at the other end of the spectrum. She'll be much slower than the normal, not ahead of them. But what's normal?

Taking Control

Having the infant at home allowed the mother to make decisions regarding infant care. All of the mothers made statements which demonstrated their desire to do the best possible for the baby. In the hospital, Sandy was confused by the mixed messages she got about feeding the baby. However, once she had the baby at home she made a decision regarding breastfeeding and the infant began to gain weight:

> I would say the only hindrance, it was very difficult 'cause every shift, three shifts you were getting conflicting messages about feeding her, we gavaged her, we fed her by bottle, we fed her with the little nipple, I pumped

> milk....When we got out we knew what we were doing so that was good too 'cause we sort of could get away from the conflict and just okay once we've made this decision we're going with it and we'll see if it works and of course she just started gaining like crazy.

Sandy was angry with herself for relinquishing some of her control over the baby's care when she took the baby back to have some blood drawn at a laboratory:

> She laid her down on the table and I took her clothes off and she [the technician] started jabbing and I wasn't holding her and she [the baby] held her breath and she went nuts and I've never seen her go like that....and I guess I grabbed her and then she did it and it was okay. I felt really guilty about that because I should have taken control of that situation and I didn't.

The desire to do the best possible for the baby could be heard in Sandy's following comment:

> But I mean, you know, I know I'm her caregiver and I know she, I'm sure there is a bond there. I'm sure she knows who I am and at least I could see that she was so much more settled when I was holding her. I mean it was terrible but I, she wasn't like she had been abandoned. And that is how she was when she was on that table and that was terrible.

Two of the mothers had to experience the rehospitalization of a sick infant. Both of these mothers did not like having their infant in the hospital but felt that it was the best place for the infant under the circumstances. Norma was upset the first time she had to take her infant back to the hospital with croup. However, with each additional rehospitalization Norma experienced relief that her infant would receive the help that she needed:

> It's the best place for her. Her saturation level was, she wouldn't eat. She hadn't ate decently for a week. Like she wouldn't drink, like she'd take an ounce and she wouldn't eat her solids. And I mean this kid can't afford not to do that....Yeah, well she needs it, it used to bother me but not anymore. I mean it's [the hospital] the best place for her if she is sick, sick, sick.

After accepting that her infant has Down Syndrome, Sally said she wanted to help her in any way possible:

> I look at it this way, there's nothing that I can do about it, she's going to stay with it, so I have to accept it. And do whatever I can to help her out.

Often the mothers were unsure about what they should be doing to help their baby. All of the mothers, except for Mary contacted an early intervention program to learn about early stimulation. Sally's reason for becoming involved in the early intervention program:

> Yeah, you don't know, 'cause they say they need so much extra work and then you don't know what to do with them. So this way now I'll start something and I'll know what I am suppose to be doing.

Each of the mothers thought that it was important for them to be involved in stimulating the baby to develop to their full potential. Norma found that taking care of the baby was a big responsibility.

Norma:

> Yeah, well not work but you always feel that there is something more that you should do, more exercises or more stimulation, or more this or more that.

After bringing the baby home, each mother said that she did not want to return to work because she wanted to be involved in the early stimulation. However three of the five mothers decided for financial reasons that they had no choice but to return to work. Sally had concerns about being at work when the early intervention worker was working with the baby:

> I might just skip out of work the day that they are going to be there for an hour or two, make arrangements and be there. I just don't want to feel left out I guess. It's the beginning part for her and I don't want to miss that part.

The mothers that returned to work said that it was important to make adequate plans for child care so that the baby would not miss out on the necessary stimulation. Sally's mother was going to babysit for Sally and have the early intervention worker come to her home while she babysat. Terry worked evenings so that her husband could be with their children. Norma found a babysitter:

> And I think the question is whether your child will get the same stimulation and the same exercises if you are with them all the time. I've found a babysitter, at least for Lynn...she's [the babysitter] excellent. So I don't have as many misgivings as I did.

The two mothers that decided to stay home to care for their infants felt that they could provide the best possible care. Sandy explained why she wanted to stay home with the baby:

> Because I want to spend my time with her, I mean you just, why not? I mean you can give her the best I think. Listen to me. Dumb mom can give the best education. You know you do tons of stuff with them and so why deprive them of it. ...well there is just no way I would leave her with somebody else, well I mean I felt that way with him too. But with her, it's just, like not even negotiable.

Maternal Perceptions of Competence in Maternal Role

Integration of the Infant into the Family

Once the infant was at home, family involvement with the baby helped to reestablish roles and relationships of family members. Sandy tried to explain how the addition of a new family member altered their family life:

> It's quite different with the second one where you really have to adjust well particularly when you're at home during the day, the threesome and the interaction. Like when you husband's there, that's different because there are two people to draw from but when it's just you, you have to work out a whole new set of rules and demands and it gets, it's a little, you get smarter on that one too.

This same mother described how she made preparations to accommodate her son before trying to breastfeed the new infant.

Sandy:

> You get creative before you nurse. You get the piece of apple cut up and go with him or you get Sesame Street on or you just think of different things or you try to get him to read a book with you or whatever.

It was common for the mothers to find similarities between the new infant and other family members in both appearance and personality. This comparison of family members represented an acknowledgement of the integration of the baby into the family circle. Both Norma and Sally found similarities between the infants' eyes and other family members' eyes.

Norma:

> Uh, she had large eyes like her brother, her dad's colour.

Sally:

> Yeah, she's got his eye features, his long eyelashes, his same eyelashes as him and a little mouth like him.

One of Mary's children from her previous marriage was described as being a loveable child, Mary predicted that the new infant would have a similar personality:

> Just for no reason at all give you a great big hug, that's the way Reg is and I think John is going to be like that.

All of the mothers said that they took the baby every where that they would have taken any new baby. Norma said the baby was part of the family:

> She's part of the family and she just struts along with everybody else....I don't know how

> much we changed because she is her. Or whether because we have a new baby. I think probably somewhat of both. We take her and she goes the same place we would take any new baby.

The mothers felt that it was important for them to feel that the extended family had accepted the baby into the family. Sandy was pleased when her niece included the baby in their plans to go to the park:

> ...my sister, said um she wanted to, she phone up and asked or she talked to her kids and she said, Do you want to go to the park with Auntie Sandy and Fred? And her oldest daughter who is three said, What about baby Miranda? And I said "Well you can tell Carol she warms my heart." Like we're not leaving Miranda behind.

After the baby's grandfather was told of the Down Syndrome, Mary watched for his reactions to the baby:

> Yes he was fine, after that time I particularly paid took notice you know...actually he was more attentive afterwards. You know there was everybody, I mean there was so many darn grandchildren there, time had to be shared anyway but he would talk to John you know and he'd take more notice of John and all this and that so I felt good.

Sally perceived that her family's acceptance of the infant would influence how her child would feel about herself in the future:

> ...but they came and held her and played with her and talked to her. They weren't afraid to hold her, so that was a good sign. So I think she'll do good.

Integration of Infant into the Community

After learning more about Down Syndrome, Norma felt that society was better prepared to accept people with Down Syndrome as members of the community.

Norma:

> And then you learn that things really aren't as bad as you had originally thought they were. I mean the diagnosis is the same but the Down's kids certainly have a place now. Much more so than they did.

It was important to the mothers that their infant would become accepted by the community. Sandy was pleased to see an adult with Down Syndrome attending her church and she saw this as a sign of acceptance by the community:

> And I thought there you go, no big deal, he's going to church and no fuss one way or the other. He's just accepted as a member of the community so I think that's what I want for her certainly.

Norma saw her infant as becoming accepted in the community:

> Everybody knows her...I go to the grocery store and "How's your daughter?" Or we go to the drug store and "Here's Lynn's mom. Now how's Lynn doing?"

Sally also felt that her baby was being accepted in the community:

> Oh yeah, the girls in here, the neighbors come for coffee and they want to play with her and they phone and say "Well come for coffee but make sure you bring the baby with you."

Taking One Day at a Time

The mothers found that establishing a daily routine helped them to focus on the present. Although the mothers still had concerns about the future, all of them found that it was important to cope with one day at a time. Norma was aware that she would have to contend with a number of potential problems in the future:

> You don't know how, you just take one day at a time. You learn, we are learning I suppose all the time. But in particular, you learn that you don't learn what hasn't come yet. We're learning to do that because it's uh, I can't, I can't be concerned at this point what the speech is going to be or what her reading level is going to be or what this going to be. It's only one thing at a time.

Both Sally and Mary said that they did not "dwell on the future". Sally said she coped by taking "it day by day". Mary said that if she was to worry about the future she would "go crazy" because the infant was so young and she would know more about her infant's potential by age three:

> I don't even think about it at all because there's no point really. All I need to do now is know what's available to me and then when the time comes....I guess we just take um a day at a time if you want to put it that way 'cause there's not really too, too much to talk about until I can find out some answers from these other people ah and their thoughts as far as whenever the time comes around that they think that John would be able to go to regular school or whether he has to have extra help or this and that because until that time there's really not that much to talk about.

Norma's advice for other new mothers with an infant with Down Syndrome was:

> Probably just to take one day at a time. You can't worry about what hasn't happened.

Sandy agreed that it was important for parents of an infant with Down Syndrome not to worry about the future:

> Well that's true too, you do figure that out pretty quick 'cause here you are with this little baby that is so apparently normal and you're thinking "Why am I bothering my brain about when she is thirty, let's enjoy her babyhood." You do that, and you come to that reckoning pretty quick.

Competence/Confidence in Maternal Role

All of the mothers perceived themselves to be competent in mothering their infant with Down Syndrome. Mary considered herself to be a "really excellent mother" and had confidence in her ability to care for the infant. She did not like to leave her infant to be cared for by anyone else as she thought that she would be able to provide the best care. Norma also said that she had no problems caring for her infant:

> I don't think I have any problems. No, I think we are coping just fine. Actually, I'm sometimes surprised that we cope as well as we do.

Norma felt confident that she could cope with any other problems she might have to face with her daughter:

> I mean I'm beginning to wait for the axe to fall or something. I'm not looking forward to the surgery. That's okay though, we'll manage to get through that the same as we managed to get through the other things.

Both Norma and Sandy referred to the mother-infant "bonding" that occurred in the development of their relationship with the infant. Norma said that this relationship was similar to her relationship with her other child:

> I don't see my relationship with her any different than it was with my son really...I care for her the same as I cared for her brother.

Sandy said that her relationship with this baby was "special" because of the infant's affectionate responses, especially during breastfeeding. Sandy:

> The body contact and she's so funny when she nurses because she holds you, they're really touchy little babies and when I hold her she pats me, she pats me when I pat her. She's so affectionate I couldn't believe it. Like you know people say kids with Down Syndrome are affectionate but already she is. I love it. She smiles a little bit...and she's cuddly and huggy. Good eye, nice eye contact, that type of thing.

Sally was confident that her relationship with her infant was good:

> I think we've been good together, she knows who I am and I know who she is.

When asked how she knew that she was a good mother to the baby, Sally replied:

> She doesn't cry and I know she's being fed, she's always changed. She doesn't have a rash on her behind. She's well dressed. I think those are good signs and every time somebody, these are friends or ours, they say how cute she is, you know her outfit is nice on her. That makes me think that I am a good mother.

Sandy also saw herself as a "good mom" but thought she might benefit from becoming involved in an early intervention program:

> I think I'm doing a good job but you think yeah I probably do need more, I do need help and that. And I'm looking forward to when we get her into, with the early intervention program. Well I'm looking forward to that just because I think you probably get ideas what you may think of but you might not too. Mothers naturally think of things surprisingly, by accident.

This same mother thought that her previous experience with motherhood helped her to be more confident at making decisions regarding infant care:

> More confidence and it just comes naturally like you really, it's not even a conflict in your brain or up for discussion, you just know. And you know from the past experience of the way things have evolved you have the confidence of having seen it happen. And you just think, we'll know when it's right, no big deal.

Observations of Maternal-Infant Interaction

During the interviews, the researcher observed the interactions between the mothers and the infants. All of the mothers demonstrated affection for their baby by cuddling, holding, and kissing the infants. The mothers and infants frequently seemed to make eye contact when the mothers were holding them. All of the study mothers, except for Sally spoke directly to the infants in quiet soothing tones. When the infants began to cry during the interviews, the mothers responded immediately by picking their infant up, consoling the infant and identifying the infant's need. There was only one situation in which one of the mothers was unable to console the infant. In this situation, Mary tried to identify the infant's need by changing his diaper, offering a bottle and holding the baby. Since the infant continued to fuss, she placed him in his bed and completed the interview while listening to the baby over the monitor. As the interview came to a close, the baby began to cry louder and Mary returned to pick him up. Mary's inability to meet her baby's need in this particular circumstance did not seem to indicate any problem with their relationship. The researcher did not observe any interactions which suggested problems in any of the mother-infant relationships.

Findings from the Maternal-Child Relationship Evaluation (MCRE)

All of the mothers, except for Mary returned the completed questionnaire within a couple of weeks after receiving it. Although a follow-up phone call was made to Mary regarding the questionnaire, the instrument was never returned to the researcher. Mary was having some marital difficulties which she felt were absorbing all of her energy and may have prevented her from completing the questionnaire.

The results from the returned questionnaires reveal that each of these mothers had scores that provide additional validation for the descriptive evidence for acceptance of their infant. During the first interview, Norma was asked to describe her relationship with her infant:

> I've been a little more protective I think. Umm, maybe a little closer, I don't know, because of that, you know, protection. Certainly never a rejection, or that kind of thing.

The results of the MCRE verified Norma's acceptance of the infant with a score for acceptance above the 99th percentile. The scores of overindulgence and rejection were in the moderate range between the 25th and 30th percentiles. These scores suggest high acceptance and a wholesome expression of slight overindulgence and rejection (Roth, 1980). Although Norma thought that she was more protective with this infant, the MCRE score for overprotection was below the 5th percentile.

At the time of the completion of the questionnaire, Sandy's daughter was the youngest of the study infants, at five months of age. Sandy's acceptance score was in the moderate range at the 60th percentile suggesting that more time is needed for the mother-infant relationship to develop. However, her three scores for overindulgence, overprotection and rejection were all below the 25th percentile providing additional evidence for an accepting relationship. Sandy did not like the questions in the MCRE and "found the wording in many of the statements offensive". She sent a letter attached to the returned questionnaire which described her disagreement with the wording in the MCRE and the resulting difficulty she had in agreeing with the statements. This mother thought that the statements were misleading and she was unable to comfortably choose responses which represent her attitude towards child rearing.

All of Sally's scores fell in the moderate range between the 30th and 70th percentile. Roth (1980) says that scores in this range have a larger error estimate and are more difficult to interpret. Sally's highest score was for acceptance suggesting that the mother is accepting of the infant. However, the small range of difference between the scores suggest some confusion on the part of the mother in her feelings toward the infant. The mother's confusion may be due to the stress that the mother was experiencing with a change in her infant's health status. At six months of age the baby had been hospitalized for an upper respiratory infection at which time the doctors decided that it was necessary to perform heart surgery as soon as possible to correct a heart defect. Although the mother had been informed of a heart defect at the time of the birth, she had been told that the defect was small and would not need repair until the child was about two years of age. The mother completed the MCRE when the infant was about eight months old which is the same time that the impending heart surgery was to be done. The sudden nature of the need for heart surgery was an additional stress for the mother to cope with and had the potential for affecting the developing maternal role and attitude toward the infant.

Summary

In this chapter, the process of maternal role formation was illustrated using selected comments of study informants. The maternal-infant interactions observed by the researcher verified the maternal-infant attachment which each mother described when asked about their relationship with the infant. In addition, the MCRE scores provide some support for the observed and reported maternal acceptance of the infants in this study.

The following chapter summarizes the findings from this study and relates them to existing literature on the topics of maternal-infant attachment, maternal response to the birth of a handicapped child and maternal role attainment. An examination of the limitations of the study and the implications for nursing practice, education and research arising from the study will be addressed in the final chapter.

Chapter V

CONCLUSIONS, DISCUSSION AND IMPLICATIONS

The purpose of this study was to develop, conceptualize and describe the process of maternal attachment to an infant with Down Syndrome. The research questions guided the discovery of the factors described by the informants which influenced maternal attachment to their infants. In addition, the maternal perceptions of their developing relationships with their infants was explored at particular points in time and over time.

Conclusions

Given the small sample size, conclusions drawn from the research must be tentative. When compared to the literature, it would appear that mothers of infants with Down Syndrome progressed through a similar process of maternal-infant attachment to mothers of normal infants. Since the term attachment was not defined for the informants prior to data collection, the mothers described their relationships with the infants in terms of bonding, caring for, feeling good about being with the infant and knowing one another. These maternal descriptions of their relationship with the infant fit the general description of maternal-infant attachment suggested by Gottlieb (1978). Since the informants expected a normal infant, the prebirth relationship with the unborn infant acted as an impetus for the ensuing development of maternal-infant attachment. The developing maternal role allowed the study mothers a means for the expression of her attachment to the infant following the birth.

There were some differences from the normal process of maternal-infant attachment experienced by these mothers, as a result of the grief reactions associated with having a handicapped infant. The diagnosis of Down Syndrome dampened the mother's desire to take on the maternal role which stalled the process of maternal role formation. The grief experienced by these mothers appeared to delay the attachment process as the mothers needed time and energy to gain an understanding of the condition and accept the responsibility for caring for the infant. In addition, the knowledge that children with Down Syndrome have a limited potential for growth and development seemed to hinder the mother's initial desire to develop a longterm relationship with the child. The presence of an abnormality in the infant did not prevent maternal-infant attachment over time for the mothers in this study.

This chapter will include a comparison of the findings presented in this paper with the information found in a review of the literature concerning the process of maternal-infant attachment, maternal response to the birth of a handicapped child and maternal role attainment. In addition, an examination of the limitations of the study will be discussed followed by the implications of the study for nursing practice, education and research.

Overview of Process of Maternal Role Formation

In this study, the process of maternal role formation was initiated by the birth of an infant with Down Syndrome. As illustrated in Figure 2, seven general steps in the process were identified beginning with the prebirth expectations for the maternal role and ending with maternal perceptions of competence in performing the maternal role. It is expected that mothers of "normal" infants would proceed through a similar process of maternal role formation. The differences in the process for mothers of infants with Down Syndrome are found in the two steps, "maternal reaction to diagnosis" and "informing others of diagnosis". The steps in the process were completed in conjunction with particular events in time and were influenced by certain factors. The factors which were identified by the researcher, through the research, as influencing the development of maternal-infant attachment were:

1) knowledge of Down Syndrome;
2) prior experience with handicapped children;
3) previous experience with motherhood;
4) timing and manner of being informed about the Down Syndrome;
5) support from health care workers;
6) spiritual support;
7) involvement in caring for the infant;
8) support/non-support from family, friends and others;
9) acceptance by the family and community;
10) the infant's normal attributes and/or health status;
11) focusing on the present.

The informant's progression through the steps of the process eventually resulted in the formation of a new role as the mother of an infant with Down Syndrome. It is important to note that while the steps appear to be linear, a recycling of parts of the process may occur as the mother gradually adjusts to the knowledge and experience of having a child with Down Syndrome. In this section, a comparison of the findings for each step in the process will be made with the literature reviewed on the topic of maternal-infant attachment and maternal response to the handicapped child. Following this discussion, a comparison of the findings from this study will be made with the literature on maternal role attainment.

Prebirth Expectations for Maternal Role

All of the mothers in this study were aware of the possible risk of a fetal abnormality with any pregnancy. Klaus and Kennell (1982) say that it is common for mothers to have hidden fears that an infant may be abnormal. Two of the study mothers were aware of the increased risk of a chromosomal abnormality in their fetus due to advanced maternal age. However the normal healthy pregnancies which all of the study mothers experienced suggested to them that their newborns would be normal. In a study of maternal attachment, Stainton (1985b) referred to the maternal interpretations regarding the health of the developing infant as "reassurance from the body".

Although Mary had initially considered terminating the pregnancy, her anticipation for the expected child escalated with her husband's growing excitement. Both Leifer (1980) and Lederman (1984) note that a husband's support during pregnancy can influence the mother's feelings about the pregnancy. All of the mothers said they were looking forward to being the mother of a healthy infant. This maternal anticipation for the infant suggests that maternal attachment begins during the pregnancy, as identified by several previous researchers (Bergum, 1989; Cranley, 1981; Leifer, 1980; Rubin, 1977; Stainton, 1985b).

Initiation of Process of Maternal Role Formation

The infant's gender and health status were important factors affecting the mother's relationship with the infant and their ability to care for the baby. The two mothers with small babies also found that the infant's size contributed to the difficulties that they experienced in getting to know the infant following the birth. This data supports the work of Rubin (1977) which states that gender, size and condition of the infant is paramount to identification of the infant by the mother and an integral part of the process of binding-in.

Maternal Reaction to Diagnosis

In studies involving the births of handicapped children, several researchers have reported that maternal-infant attachment is promoted by early maternal contact with the infant (Drotar, Baskiewicz, Irvin, Kennell, Klaus, 1975; Klaus and Kennell, 1982; Waechter, 1977). These researchers suggest that early parental contact with the infant serves to minimize the parents' estrangement from their child by emphasizing the infant's normal attributes (Drotar, Baskiewicz, Irvin, Kennell, Klaus, 1975). Before being informed of the diagnosis, each of the mothers in this study had the opportunity to hold their apparently normal newborns. The mothers recalled the pleasure and excitement that they experienced during this time spent with their spouse and infant. These findings also support the work of Stainton (1985b) which described the reassurance that a mother feels about the health of the infant when holding the newborn. Following the diagnosis, two of the mothers experienced separation from their infants which they described as "traumatic" and "difficult". Other researchers have reported that separation from the infant after birth hinders that mothers ability to get to know the infant (Klaus and Kennell, 1982; Waechter, 1977; Winzer, 1987) and thus question their own ability as a mother (Bergum, 1989).

The mother's reaction to being told of the diagnosis of Down Syndrome was affected by the timing and the manner in which they were informed as suggested by a large volume of literature (Butani, 1984; Carr, 1970; Edelstein and Strydom, 1981; Fost, 1981; Gilmore and Oates, 1977; Pueschel, 1985; Sahin, 1978; Shiono and Kadowaki, 1979). Although the mothers thought that it was important to be told of the diagnosis soon after the birth, they also thought that the physicians should consider other factors before informing them. Norma thought she should have been given more time to recover from the labour and delivery before being informed of the diagnosis. This was a similar reaction to some of the women studied by Drillien and Wilkinson (1964). Shiono and Kadowaki (1979) recommend that the mother's physical status should be assessed prior to deciding if she can cope with the stressful information about the child. Both Sally and Norma thought that the physician should have waited for their spouse to return to the hospital before informing them of the diagnosis of Down Syndrome. Much of the literature supports the need for the presence of the spouse before telling the mother about the diagnosis (Carr, 1970; Gayton and Walker, 1974; Gilmore and Oates, 1977; Pueschel, 1985; Shiono, and Kadowaki, 1979). However as noted by Carr (1970), it is not possible to lay down hard and fast rules, as to whether the parents should be told together or alone, since each family may have different needs. For example, Mary thought that it was appropriate that she was informed as soon as the diagnosis was made because she had requested the pediatric assessment following the birth. In situations similar to this, the information should not be delayed, while waiting for the other spouse to arrive (Carr, 1970). Therefore, while the information on the infant's condition should be provided in the presence of both parents under usual circumstances, each situation should be assessed prior to the initial information session.

The manner in which the mothers were told about the Down Syndrome influenced the mother's reaction to the diagnosis. Norma expressed anger at being told about the diagnosis by a "stranger" who spoke to her briefly and then left her alone in the room. Mary said that the physician who told her about the diagnosis was "unfeeling" but that her own physician was supportive. Both Mary and Norma said that a familiar physician should be present at the time of being informed. Norma also thought that physicians in training should learn "better ways" to tell mothers about Down Syndrome. The mothers who were satisfied with the manner in which they were informed of the Down Syndrome described the physicians approach as honest, supportive, polite and explanatory. These findings closely approximate previous literature which suggests that the three most common characteristics used by parents to describe a helpful health professional during a counselling session are honest (Butani, 1984; Carr, 1970; Fost, 1981; Pueschel, 1985; Sahin, 1978), supportive (Antley and Hartlage, 1976; Butani, 1984; Carr, 1970; Drotar, Baskiewicz, Irvin, Kennell, Klaus, 1975; Pueschel, 11985) and sympathetic (Carr, 1970; Fost, 1981). Most important to the satisfaction of the mothers is that the physician was seen as spending time with the mother rather than just informing the mother of clinical facts about the diagnosis.

Following the diagnosis, the three most commonly noted reactions by the mothers were shock, denial and grief which support the findings of Drotar, Baskiewicz, Irvin, Kennell, Klaus (1975) and Waechter (1977). Other feelings of shame, disappointment, death wish and fear described by the mothers support the work of several researchers (Childs, 1985; Drotar, Baskiewicz, Irvin, Kennell, Klaus, 1975; Gilmore and Oates, 1981; Waechter, 1977). Although maternal recognition of negative feelings may be very positive, these feelings were at times a hindrance to the process of maternal role formation. For example, three of the mothers withdrew from their infants for a period of about twenty four hours after hearing the diagnosis. This finding is supported by the results from several other studies (Brady-Fryer, 1988; Carreto, 1981; Mercer, 1974; Waechter, 1977). However, as noted by Mercer (1974) this avoidance of contact appears to be necessary for mothers to limit the dosage of stress and gain the emotional energy required to become involved in caring for the infant.

Several authors (Carreto, 1981; Waechter, 1977; Winzer, 1987) found that feeding problems with handicapped infants interrupt the mother's ability to care for the infant and can hinder the attachment process. For example, three of the mothers tried to breastfeed but had difficulty because of the problems with the infant's muscle tone and strength. Terry and Norma allowed the nurses to feed the baby for the first few days because of these feeding difficulties. Terry was disappointed with her efforts to breastfeed the infant and found that she had to rely on supplementation with formula when she went home. Following discharge from the hospital, Sandy continued her efforts to breastfeed with encouragment from the community health nurse. Sandy said she missed the "bonding with the one on one" until the infant began to breastfeed successfully at about two months of age. At that time, Sandy said she phoned the community health nurse and told her she felt like "shouting from the rooftop" to celebrate her daughter's breastfeeding success. Lack of consistency between nurses with regard to the best approach to feeding the infants hindered the mothers' efforts to initiate breastfeeding. However, after the mothers received support and encouragement from some nurses, two of the mothers were able to establish breastfeeding as part of the infants' feeding pattern. These findings support the nursing literature which describe the influence that health professionals can have on the maternal-infant attachment process.

Maternal Acceptance

All the mothers in this study experienced a sense of loss upon learning that their ideal expectations of a normal infant did not fit the actual infant with Down Syndrome. This data supports the work of several authors (Klaus and Kennell, 1982; Solnit and Stark, 1961; Steele, 1987; Waechter, 1977) who claim that one of the early tasks of parenting is to resolve the discrepancy between the actual and ideal infant so that attachment to the actual infant can occur. Steele (1987) found that parents experience profound grief following the birth of a critically ill infant and that complete grief resolution could not be expected to occur during hospitalization. Two of the mothers described recurring grief reactions at the time of rehospitalization of their sick infants. Several authors (Olshansky, 1962; Sahin, 1978; Winzer, 1987) have noted that acceptance of the handicapped child does not come all at once, rather parental sadness may resurface at critical junctures in the life of the child and family. This finding is also supported by results from previous studies (Censullo, 1986; Morgan, 1987; Waechter, 1977). The mothers in this study found that the support they received from hospital staff helped them to overcome the negative feelings related to their grief and begin to feel more comfortable about caring for their infant. Similar findings were described by Steele (1987) and Waechter (1977). The mothers involvement in caring for the infants enabled them to accept the infant and continue with the process of attachment, this is comparable to findings in two other studies (Brady-Fryer, 1988; Drotar, Baskiewicz, Irvin, Kennell, Klaus, 1975).

Informing Others

Informing others was seen as a necessary component in the development of a longterm accepting relationship with the infant. Initially the mothers found it difficult to inform others about the diagnosis of Down Syndrome supporting the work by Drotar, Baskiewicz, Irvin, Kennell, Klaus (1975).
The mothers tended to rely upon their spouse and immediate family members to tell other family and friends about the diagnosis while they were in the hospital. However, the mothers found that once they began to tell other people about their infant, it helped them to overcome denial and reinforce their

acceptance of being the mother of a child with a handicap. This data supports Waechter's (1977) claim that "openness to others" is a necessary developmental task for self-acceptance and constructive parent-infant interaction. The informant's willingness to tell people about the handicap was related to their expected response from the other person. For example, Mary was not willing to inform her ex-husband or children as she thought they would not accept the infant.

The manner in which other people responded to the infant was important as mothers tended to absorb these feelings. In an earlier study (Waechter, 1977) a similar observation was reported. For example, Norma was hurt by a stranger's negative response to the infant's protruding eyes and was unable to tell the lady that her infant had additional problems. It is posited that the baby is still an extension of the mother thus the response by others to the infant affects the mothers feelings about herself and her infant thereby affecting the attachment process (Rubin, 1977; Waechter, 1977).

Maternal Role Transition

After bringing the infants home, the mothers were able to focus on the normality of the child rather than being constantly reminded by health care workers of the abnormality. The informants found that taking care of the infant at home was no different than taking care of a normal infant, a finding which was also reported in a study undertaken by Drotar, Baskiewicz, Irvin, Kennell and Klaus (1975). The mothers' emphasis on the normal aspects of the infant's development seemed to reflect maternal adjustment to the caretaking role rather than a denial of the disability. These findings also support the work of Drotar, Baskiewicz, Irvin, Kennell and Klaus (1975). Recent literature suggests that parents prefer using a management style that has been labelled "normalization" for rearing the handicapped child (Deatrick, Knafl, Walsh, 1988). Normalization allows the parents to raise the handicapped child as they would a normal child.

Maternal Perceptions of Competence in Maternal Role

An important factor in relation to the mother's perceptions of competence was her ability to establish a new network of roles and relationships within the family which included the infant. For example, Sandy had to learn strategies which would allow her to meet the needs of her two year old son while she took time to breastfeed the new infant. The importance of the integration of an infant into the family unit has been addressed by Wright and

Leahey (1984). Part of the process of integration with any new member, includes the establishment of attachment between various members of the family and that new member, including a normal infant (Wright and Leahey, 1984). The informants looked for signs of attachment by family members to the infants and gained comfort from identifying behaviors which they perceived as accepting. Behaviors by others which demonstrate acceptance of the infant have been described by Rubin (1977) as reciprocal claiming behaviors of significant persons. Rubin (1977) describes claiming behaviors as part of the attachment process, which "binds the newborn into the exclusive and intimate social sphere" of the family. The mothers in this study demonstrated maternal claiming behaviors through their frequent comparisons of the infants with other family members.

The mothers in this study were also looking for evidence of acceptance of the infant into the community. The secondary informant, a mother of a six year old child with Down Syndrome, verified that community acceptance was an important aspect of integration. This mother said that since her daughter was already accepted in their neighborhood, the family was unlikely to move to a new area, as she did not want to have to reestablish acceptance of the child in a new community. These findings support the work of Sahin (1978) which suggest that societal acceptance of the handicapped child is important to the family.

The mothers in this study found it essential to focus on the present and "take one day at a time" in order to gain confidence in their ability to care for the infant. Although all the mothers indicated that this strategy was necessary, there was no literature found which supported these findings. However, Waechter (1977) indicates that parents may be anxious about future responsibilities and doubt their capacities for coping with such responsibilities. Therefore it is possible that the mothers focused on the present to protect themselves from additional stress and escape the potential threat from the future until they were gradually able to accept reality.

One of the study mothers found it "just too hard to dwell" on her infant's future but was able to plan for the infant's future financial security. The infant had received money through an inheritance and the mother was adding to the money. The secondary informant indicated that although she initially had to focus on the present after the birth of her infant with Down Syndrome, she was now able to plan for her six year old child's future. Therefore a potential part of the process of maternal role formation may be the mother's eventual ability to plan for the child's future.

Comparison of Findings with Literature on Maternal Role Attainment

According to Thorton and Nardi (1975), role acquisition is a process that develops over four stages: anticipatory, formal, informal and personal. The anticipatory stage occurs during pregnancy when an individual begins social and psychological adjustment to the role by learning the expectations for the role. In this study, the mothers' role expectations during pregnancy were related to their anticipation of the birth of a normal infant. Upon being informed of the Down Syndrome, the anticipatory phase of maternal role acquisition was extended as the mothers had to grieve for the loss of their expected infant and accept the reality of the actual infant.

During the mothers initial reaction to the diagnosis, their prior experience with handicapped children and their knowledge of Down Syndrome influenced the pychosocial adjustment of the maternal role expectations involved in caring for a handicapped child. Role expectations represent certain qualities and performances and make it possible for a person to enact a role (Chao, 1979). Both Sandy and Mary recalled positive childhood experiences with handicapped children which helped them to accept the maternal role of caring for a child with Down Syndrome. Nancy had secondary education which involved courses dealing with chromosomal disorders yet found her texts to be so pessimistic about the potential for children with Down Syndrome that she was unable to read them following the birth of her child. Nancy was the only mother to talk about her initial thoughts that the baby might be better off dead than surviving with Down Syndrome.

In addition, as multigravidas, all of the mothers found that their previous experience with motherhood helped them to cope with becoming the mother of a handicapped infant. The previous maternal experiences helped the informants to anticipate the actions required during labour and delivery. Following the birth, the mothers' prior knowledge of infant care assisted them in learning to care for this infant. As noted in a literature review by Chao (1979), an individual's past experiences and present attitudes play a part in determining a cognitive process. Chao's (1979) statement that knowledge can both negatively and positively affect response as the individual's understanding may distort the object world and hinder cognition is supported by these findings.

The formal stage of role acquisition (Thorton and Nardi's, 1975) begins following the birth of the infant at which time role behaviors are largely guided by formal, consensual expectations of others in the individual's social system (Mercer, 1981). The birth of the infant initiated the process of maternal role formation as the mothers became interested in holding their infant on the delivery table and caring for the infant. For example, Sandy described her anguish with being separated from the infant after birth and her desire to begin breastfeeding. These findings are also supported by the work of Gottlieb (1978), and Mercer (1981) which describe the formal stage of role acquisition as beginning with birth. The formal stage of this process continued to occur during the infant's hospitalization as the mother's involvement with the infant was guided by the nurses role in providing infant care. The mothers learned the maternal role of caring for a handicapped infant by observing the responses of nurses and other health care workers to the infant. For example, the mothers who wanted to breastfeed their infant were initially unable to do so as they relied on the nurses to gavage or bottle feed the infants for the first few days after the birth. With support from a few nurses, two of the mothers were able to learn techniques which helped them to initiate breastfeeding.

In addition, the social support received by the mothers assisted them in the transition to the maternal role as stated by Majewski (1987) and Mercer (1981). For example, Sally was able to become more involved in taking care of her infant as she received support from her family, friends and another mother of a child with Down Syndrome.

The informal stage begins as the individual develops unique ways of dealing with the role that are not conveyed by the social system. The mothers in this study found a major difference in their ability to care for the infant upon returning to their home environment, which reaffirmed the findings of Brady-Fryer (1988). The mothers described the feelings of relief at being able to return to normalcy within their own environment. Steele (1987) describes this phase of adjustment as a time when parents begin to "take hold" of their parenting roles, becoming more secure and competent in caring for the infant. The informants in this study described both fear and excitement at being in control of decisions regarding infant care rather than being under the control of health care workers. An important component of this step was the mother's desire to do the best possible for the infant. As described by Steele (1987) and Brady-Fryer (1988), the mothers became more assertive in their parenting role as they perceived health care workers to be more intrusive. For example, Sandy was unhappy with the laboratory technician's attempts to take blood from her daughter so she took control of the situation by deciding to hold the infant during the blood work.

One of the mothers in this study described feeling alienated and isolated from society after returning home from the hospital. This behaviour was also reflected in the reports on maternal behaviour in two previous studies by Mardiros (1982, 1985). Although all of the informants described themselves as the main caretaker of the child, Mary was the only mother who saw herself as having little support from others. However, Mary had recently moved to the city from another country and did not have any family or friends living nearby. In addition, Mary was the only mother that had not yet made contact with any of the agencies which provide support for children with

Down Syndrome.

Three of the informants reported feeling greater concern about returning to work with a handicapped child than with their normal children. These findings were consistent with reported concerns of mothers of handicapped children studied by Mardiros (1985).

The final stage of role acquisition is a personal state in which the mother experiences a sense of confidence and competence in how she performs the role. Using this definition of role acquisition, Mercer (1981) describes the final stage in role acquisition as the endpoint of maternal role attainment. Upon completion of the process of maternal role formation, all of the informants described with some confidence their perceptions of being a competent mother which adds further support to the theories related to maternal role attainment (Thorton and Nardi, 1975; Mercer, 1981). However, the mothers confidence in caring for the infant was related to present circumstances. These findings suggest that the process of maternal role formation may continue until the mothers have gained the confidence and competence to meet the future needs of the child.

Limitations of the Study

Although the sample selected for this study was deemed appropriate, there were difficulties in obtaining informants who met the sample selection criteria. The researcher was prevented from approaching two mothers who met the criteria but were having some apparent difficulty with adjusting to the birth of their infant with Down Syndrome. Therefore all of the informants approached to take part in the study were thought to be coping with the birth of their infant prior to entering the study.

The similarity of particular characteristics of the informants, such as multiparity, marital situation, fluency in English, and cultural backgrounds led to consistencies in the data. However, the differences in age, personal experience with handicapped children and education of the mothers undoubtably contributed to some of the variations in the findings.

All of the interviews occurred after the mother and infant had been discharged from the hospital. Therefore the descriptions of the mothers' experiences in the hospital and in the weeks after returning home, prior to the first interview were retrospective in nature. This time lapse may have altered the descriptions of the actual maternal experience. A closer examination of the early support and non-support that the mothers received in the hospital would be facilitated by earlier interviews. However, since this is a study of the mother's perspective of the process of attachment to her infant, the differences between the retrospective descriptions and actual experience may be of little importance.

The Mother-Child Relationship Evaluation (MCRE) was completed by the mothers a few weeks following the last interview. According to the MCRE manual this instrument can be administered to mothers individually or in groups. According to Roth (1980), the experimental data for the MCRE was based on a relatively homogeneous group of middle-class mothers ages 25-35 years. However, there is no mention of the age of the children on which the mother-child relationship was being measured. Following an examination of the questions it seemed that the questions were more appropriate for mothers of preschoolers or school age children than for infants. At least two of the informants said that they had difficulty completing the instrument because they found the statements on child rearing to be unclear. In addition, these mothers found it difficult to relate the statements addressed to the school age child to their infant when they were unsure of the future needs of the child. Therefore, this instrument did not seem appropriate for mothers with infants with Down Syndrome and would not be recommended for similar investigations.

Implications for Nursing

The results from this study have implications for nursing practice in a variety of settings, including the hospital, home and community. The nursing care provided to the family with a handicapped child should be guided by those variables which have been identified and supported in the literature. As noted in the literature and supported in this study, in most cases, parents should be together when informed of the infant's abnormality. An exception can be made when the mother has voiced suspicions about the infant's condition and has requested further assessment.

Ideally, a nurse should be present during the initial session when the parents are informed of the infant's condition. The nurse is then aware of the explanation that was given to the parents and can reinforce it with consistent information. In addition, the presence of the nurse during the initial session can indicate to the parents the willingness of the nursing staff to be supportive to them. As reported by Carr (1970) and supported in this study, parents perceived greater acceptance of the information, if they were told honestly and sympathetically, and that they were grateful for any comfort and support given to them during the difficult time.

The process of maternal role formation could be used by the nurse as a guiding tool to assess the progress of the mother and plan interventions accordingly. For example, a mother at the step of maternal acceptance will need to be encouraged to be involved with infant care. Nurses working in a maternity setting should be aware of the parent's extreme sensitivity to the responses of the health professionals caring for them and their infant. Butani (1984) states that the nurse can act as a role model in caring for the baby in a warm and sensitive manner. The nurse's attitude and response can demonstrate to the parents, a social acceptance of the infant. It is also important that the parents have adequate information to assist with decision making. The nurse can assess the parents level of understanding by establishing an atmosphere which is conducive for open communication to allow the parents the opportunity to voice their concerns (Butani, 1984; Waechter, 1977). In addition, the nurse should assess the mothers willingness to talk about the infant's condition and the adequacy of support that the mother is receiving from friends and family.

Following discharge from the hospital, the community health nurse should provide consistent and coordinated support for the family (Butani, 1984; Sahin, 1978). This means that the various agencies caring for the family need to communicate openly, make appropriate referrals and coordinate the health care provided to the families. Nurse to nurse referral between the hospital and the community agency could assist community health nurses to provide earlier contact with the mother of a handicapped infant following discharge home. In addition sharing of information between nurses should allow for more consistent support to the family. It is most important that the family remain in contact with a source of support so that they can continue to have access to necessary information and available community resources. The need for continued support in the community should help to prevent feelings of alienation and isolation from society as described by Mardiros (1982).

Nursing education must continue to emphasize the importance of the family and community. In this study, the support from family and friends was a necessary component in the process of maternal role formation. A promotion of the understanding of this essential ingredient will assist nurses to provide adequate and appropriate care for the mother and infant.

Implications for Future Research

This exploratory study was conducted to gain insight in to the process of maternal attachment to the infant with Down Syndrome. The exploratory nature of the study raises questions, provokes thinking and indicates areas in need of further examination and clarification. The small sample of selected informants were all multigravidas, involved in a supportive relationship and of similar cultural background. Although two of the mothers were aware of the increased risk of a chromosomal abnormality because of advanced maternal age, all of the study mothers expected to give birth to a healthy normal newborn. The success at maternal role formation exhibited by these mothers generates further research questions regarding the specific factors which influenced this process. For example:

1) How are the experiences of a group of multiparas different from a group of primiparas?

2) How are the experiences of a group of mothers with the first handicapped infant different from the experiences of a group of mothers with a second handicapped infant?

3) How are the experiences of a mother expecting the birth of a handicapped infant different from the experiences of a mother not expecting the birth of a handicapped infant?

4) How do single mothers describe the process of attachment to their infant with Down Syndrome?

5) How are the experiences of mothers with a handicapped infant different from the experiences of a mother with a "normal" infant?

6) How are the experiences of mothers with an infant with an obvious malformation different from the experiences of mothers with an infant with Down Syndrome?

All the mothers in this study were perceived to be adjusting to their newborn. Further research is required to better understand the factors which hinder the process of maternal role formation for mothers who have difficulty adjusting to the birth of their infant with Down Syndrome.

At the final stage of maternal role formation, all of the mothers described their need to focus on the present. A longitudinal study would clarify whether mothers of children with Down Syndrome continue to focus on the present as the child matures or at what point in time they prepare for the child's future. Finally, replication of the study should be undertaken with specific consideration of the affect of culture and community support services available to the mothers.

REFERENCES

Ainsworth, M. D. (1969). Object relations dependency and attachment: A theoretical of the infant-mother relationship. Child Development, 40, 969-1025.

Anneren, G., Gronowitz, J., Kallander, C., Sundqvist, V. (1986). Mothers of children with Down Syndrome have higher herpes simplex virus type 2 (HSV-2) antibody levels. Human Genetics, 72, 9-14.

Antley, R. and Hartlage, L. (1976). Psychological responses to genetic counselling for Down's syndrome. Clinical Genetics, 9, 257-265.

Avant, K. (1981). Anxiety as a potential factor affecting maternal attachment. JOGN Nursing, 10, 416-419.

Bergum, V. (1989). Woman to Mother: A transformation. Massachusetts: Bergin and Garvey Publishers Ltd.

Bowlby, J. (1958). The nature of the child's tie to his mother. International Journal of Psychoanalysis, 39, 350-373.

Brady-Fryer, B. (1988). An exploration of maternal attachment to the preterm infant. Unpublished master's thesis. University of Alberta.

Braitman, A. and Antley, R. (1978). Development of instruments to measure counselees' knowledge of Down Syndrome. Clinical Genetics, 13, 25-36.

Brown, A. (1984). Role of radiation in etiology of Down's syndrome. British Medical Journal, 288, 147-148.

Butani, P. (1984). Coping with the birth of anomalous infant. Nursing Papers, 16(1), 14-24.

Campbell, S. B. and Taylor, P. M. (1979). Bonding and attachment: Theoretical issues. Seminars in Perinatology, 3(1), 3-13.

Carreto, V. (1981). Maternal responses to an infant with cleft lip and palate: A review of Literature. Maternal-Child Nursing Journal, 10, 197-205.

Carr, J. (1970). Mongolism: Telling the parents. Developmental Medicine and Child Neurology, 12, 213-221.

Censullo, M. (1986). Home care of the high-rish newborn. JOGNN, 15(2), 146-148.

Chao, Y. (1979). Cognitive operations during maternal role enactment. Maternal-Child Nursing Journal, 8(4), 211-274.

Chenitz, W. C. and Swanson, J. (1986). From Practice to Grounded Theory. Menlo Park, CA: Addison-Wesley Publishing Company.

Childs, R. (1985). Maternal psychological conflicts associated with the birth of retarded child. Maternal-Child Nursing Journal, 14, 175-182.

Coleman, M., Olson, D. (1987). Medical conditions that affect learning. In P. Knoblock (Ed) Understanding Exceptional Children and Youth, 69-97. Boston: Little, Brown and Company.

Corbin, J. (1986). Qualitative data analysis for grounded theory. In W. Chenitz and J. Swanson (eds), pp. 91-101, From Practice to Grounded Theory. Menlo Park, CA: Addison-Wesley Publishing Company.

Cranley, M. S. (1981). Roots of attachment: The relationship of parents to the unborn. Birth Defects: Original Article Series, 17(6), 59-83.

Cunningham, C. (1982). Down's Syndrome: An Introduction for Parents. London: Souvenir Press Ltd.

Cunningham, C. and Sloper, T. (1977). Parents of Downs's Syndrome babies: Their early needs. Child: Care, Health and Development, 3, 325-347.

Deatrick, J., Knafl, K., Walsh, M. (1988). The process of parenting a child witha disability: Normalization through accomodations. Journal of Advanced Nursing, 13, 15-21.

Down, J.L. (1866). Observation on ethnic classification. London Hospital Report, 3, 229-262.

Drillien, C. and Wilkinson, E. (1964). Mongolism: When should parents be told?. British Medical Journal, 1306-1307.

Drotar, D., Baskiewicz, A., Irvin, N., Kennell, J., Klaus, M. (1975). The adaptation of parents to the birth of an infant with a congenital malformation: A hypothetical model. Pediatrics, 56(5), 710-717.

Edelstein, J. and Strydom, L. (1981). The doctor's dilemma: How and when to tell parents that their child is handicapped. South Africa Medical Journal, 534-535.

Featherstone, H. (1980). Difference in the Family: Life with a disabled child. Beverly Hills: Sage Publication.

Field, P.A. and Morse, J. (1985). Nursing Research: The application of qualitative approaches. London: Croom Helm.

Fleischman, A., Fryd, S. (1980). The birth of an abnormal child. In B. Blum (Ed) Psychological Aspects of Pregnancy, Birthing and Bonding, 294-307. New York: Human Sciences Press.

Fost, N. (1981). Counseling families who have a child with a severe congenital anomaly. Pediatrics, 67(3), 321-324.

Gay, J. (1981). A conceptual framwork of bonding. JOGN Nursing, 10, 440-444.

Gayton, W. and Walker, L. (1974). Down Syndrome: Informing the parents. American Journal of Diseases in Children, 127, 510-512.

Giller, E., Rotnem, D., Hsia, Y., Leigh, H. (1981). Psychosocial care in medical genetics clinic. General Hospital Psychiatry, 3(2), 171-178.

Gilmore, and Oates (1977). Counselling about Down's Syndrome: The parents' viewpoint. The Medical Journal of Australia, 600-603.

Gerver, J. (1983). The grandparent's view. Child Today, 12(6), 8-11.

Glaser, B. (1978). Theoretical Sensitivity: Advances in the methodology of grounded theory, pp. 74-81. Mill Valley, CA: Sociology Press.

Glaser, B. and Strauss, A. (1966). The purpose and credibility of qualitative research. Nursing Research, 15(1), 56-61.

Glaser, B. and Strauss, A. (1967). The Discovery of Grounded Theory: Strategies for qualitative research. New York: Aldine Publishing Company

Goodman, S. and Taylor, P. (1979). Bonding and attachment: Theoretical Issues. Seminars in Perinatology, 3(1), 3-13.

Gordenuk, A. (1976). Motherhood and the less than perfect child: A literary review. Maternal-Child Nursing Journal, 5(2), 57-68.

Gottlieb, L. (1978). Maternal attachment in primiparas. JOGN Nursing, 7(1), 39-44.

Greenswag, L. (1983). Coping with birth defects: How to help. Occupational Health Nursing, 31(10), 21-23.

Hammersley, M. and Atkinson, P. (1983). Ethnography: Principles and Practice. New York: Tavistock Publications.

Holaday, B. (1987). Patterns of interaction between mothers and their chronically ill infants. Maternal-Child Nursing Journal, 16(1), 29-45.

Hook, E. (1981). Rates of chromosomal abnormalities at different maternal ages. Obstetrics and Gynecology, 58, 282-285.

Hopkins, G. (1983). If you see a Down's syndrome individual, don't jump to conclusions. Journal for Special Educators, 19(3), 52-54.

Hosack, A.M. (1968). A comparison of crises: Mothers' early experiences with normal and abnormal first-born infants. Unpublished dissertation. The Harvard School of Public Health, Boston.

Hurd, J. M. (1975). Assessing maternal attachment: First step toward the prevention of child abuse. JOGN, July/August, 25-30.

Jacob, P. A., Baikie, A. G., Court-Brown, W.M., Strong, J. A. (1959). The somatic chromosomes in mongoloism. Lancet, 1, 710.

Kennell, J. H. (1987). Keynote address: The human and health significance of parent-infant contact. Journal of AOA, 87(9), 120-128,

Kihlstrom, A. (1983). A very special boy: The parent's view. Child Today, 12(6), 8-11

Klaus, M. H. and Kennell, J. H. (1976). Maternal-infant Bonding. St. Louis: The C. V. Mosby Company.

Klaus, M.H. and Kennell, J. (1982). Parent Infant Bonding. St. Louis: The C.V. Mosby Company.

Klaus, M. H. and Kennell, J. (1983). Parent to infant bonding: Setting the record straight. Journal of Pediatrics, 102(4), 575-576.

Lamb, M. E. (1982). Early contact and maternal-infant bonding: One decade later. Pediatrics, 70(5), 763-768.

Lederman, R. (1984). Psychosocial Adaptation in Pregnancy: Assessment of seven dimensions of maternal development. Englewood Cliffs, NJ: Prentice-Hall.

Leifer, M. (1980). Psychosocial Effects of Motherhood: A study of first pregnancy. New York: Praeger Publishers.

Lejeune, J., Gautier, M., Turpin, R. (1959). Etude des chromosomes somatiques de neuf enfants mongoliens. Academie de Science, 248, 1721-22.

Low, T. W. (1984). Mother-child relationship evaluation. In D. Keysen and R. Sweetland (eds.), pp. 440-443, Test Critiques. Kansas City, Mo.: Test Corp. of America.

Lycett, R. (1982). The caring network. Nursing Mirror, 155, p.52.

Majewski, J. (1987). Social support and the transition to the maternal role. Health Care for Women Internatinal, 8, 397-407.

Mardiros, M. (1982). Mothers of disabled children: A study of parental stress. Nursing Papers, 14(3), 47-56.

Mardiros, M. (1985). Role alterations of female parents having children with disabilities. Canada's Mental Health, 33(4), 24-26.

Matsumaga, E., Tonomura, A., Oishi, H., Kikuchi, Y. (1978). Reexamination of paternal age effect in Down's syndrome. Human Genetics, 40, 259-269.

Mercer, R. (1974). Mothers' responses to their infants with defects. Nursing Research, 23(2), 133-137.

Mercer, R. (1981). A theoretical framework for studying factors that impact on the maternal role. Nursing Research, 30(2), 73-77.

Mercer, R. (1985). The process of maternal role attainment over the first year. Nursing Research, 34(4), 198-204.

Milstein-Moscati, I. and Becak, W. (1981). Occurrence of Down syndrome and human sexual behaviour. American Journal of Medical Genetics, 9, 211-217.

Mishler, E. (1979). Meaning in context: Is there any other kind. Harvard Educational Review, 49(1), 1-19.

Morgan, S. (1987). Parental Grief Following the Loss of an Infant in NICU. Unpublished master's thesis. University of Alberta.

Morse, J. (1986). Quantitative and qualitative research: Issues in sampling. In P. Chinn (ed) pp. 181-191, Nursing Research Methodology: Issues in nursing. Maryland: Aspen Press.

Nelson, S. (1985). Attachment theory. Nurse Practitioner, (August), 34-36.

O'Connor, S, Vietze, P., Sherrod, K., Sandler, H., Altemeier, W. (1980). Reduced incidence of parenting inadequacy following rooming-in. Pediatrics, 66, 176.

Olshansky, S. (1962). Chronic sorrow: A response to having a mentally defective child. Social Casework (April), 191-195.

Pueschel, S. (1985). Changes of counseling practices at the birth of child with Down Syndrome. Applied Research in Mental Retardation, 6, 99-108.

Peuschel, S. and Murphy, A. (1975). Counseling parents of infants with Downs's Syndrome. Postgraduate Medicine, 58(7), 90-95.

Reichardt, C.S. and Cook, T.D. eds. (1979). Qualitative and Quantitative Methods in Evaluation Research. Beverly Hills: Sage Publications.

Robson, K. S. and Moss, H. A. (1970). Patterns and determinants of maternal attachment. The Journal of Pediatrics, 77(6), 976-985.

Roth, R. (1980). *The Mother-Child Relationship Evaluation Manual*. Los Angeles, CA: Western Psychological Services.

Rubin, R. (1975). Maternal tasks in pregnancy. *Naternal-Child Nursing Journal*, *4*(3), .

Rubin, R. (1977). Binding-in in the Postpartum Period. *Maternal-Child Nursing Journal*, *6*(2), 67-75.

Rubin, R. (1984). *Maternal Identity and the Maternal Experience*. New York: Springer Publishing Company.

Sahin, S. (1978). On the family with a special-needs child. *Nursing Forum*, *17*(4), 357-374.

Salariya, E. and Cater, J. (1984). Mother-child relationship: FIRST score. *Journal of Advanced Nursing*, *9*, 589-595.

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

Shiono, H. and Kadowaki, J. (1979). The questionnaire to parents of children with the Down Syndrome: How to inform the parents and psychological responses to counseling. *American Journal of Medical Genetics*, *4*, 215-218.

Solnit, A. and Stark, M. (1961). Mourning and the birth of a defective child. Psychoanalytic study of the child, 16, 523-537.

Stainton, M. C. (1985a). The fetus: A growing member of the family. Family Relations, 34, 321-326.

Stainton, M. C. (1985b). Origins of attachment: Culture and cue sensitivity. Unpublished dissertation. University of California, San Francisco.

Stainton, M. C. (1986). Parent-infant bonding: A process, not an event. Dimensions in Health Services, 63(3), 19-20.

Steele, K. (1987). Caring for parents of critically ill neonates during hospitalization: Strategies for health care professionals. Maternal-Child Nursing Journal (1987), 13-27.

Stene, J., Fischer, G., Stene, F., Mikkelsen, M., Petersen, E. (1977). Paternal age effect in Down's syndrome. Annals of Human Genetics, 40, 299-306.

Stern, P. (1985). Using grounded theory method in nursing research. In M. Leininger (ed), pp. 149-159, Nursing Research Methodology: Issues in nursing. Maryland: Aspen Press.

Stone, N. (1967). Family factors in willingness to place the mongoloid child. American Journal of Mental Deficiency, 72, 16-20.

Taylor, S. and Searl, S. (1987). The disabled in America: History, Policy, and Trends. In P. Knoblock (ed.) Understanding Exceptional Children and Youth. Boston: Little, Brown and Company.

Thomas, D. (1983). Case study. Nursing Mirror, 156(25), supplement.

Thorton, R. and Nardi, P. (1975). The dynamics of role acquisition. American Journal of Sociology, 80. 870-885.

Veach, S. (1983). Down's Syndrome: Helping the special parents of a special infant. Nursing, 13(9), 42-43.

Waechter, E. (1977). Bonding problems of infants with congenital anomalies. Nursing Forum, 16(3,4), 298-318.

Whaley, L.F. and Wong, D. M. (1979). Nursing are of Infants and Children. St. Louis, MO: C.V. Mosby.

Winzer, M. (1987). In M. Winzer, S. Rogow, S. and C. David (eds) Exceptional Children in Canada. Scarborough: Prentice-Hall Canada Inc.

Wright, L. and Leahey, M. (1984). Nurses and Families: A guide to family assessment and intervention. Philadelphia: F.A. Davis Company.

APPENDIX A

SAMPLE GUIDING QUESTIONS

SAMPLE GUIDING QUESTIONS

Appropriate Questions for Initial Interview

How are you feeling about the birth of your baby?

Probes: Was this a planned pregnancy?
How are you feeling now about the baby?
How are you feeling about the diagnosis?
How do you feel about having a baby born with Down Syndrome?

How did you learn about the diagnosis of Down Syndrome?

Probes: Who told you?
How were you told?
Who was present when you were told?
How do you feel about the way you were told?

What was your immediate reaction to learning that the baby had Down Syndrome?

Probes: Was the diagnosis expected or were you surprised?
Prior to learning of the diagnosis, did you have any indications that there may be something wrong with the baby?
Was your pregnancy normal?

How are you and the baby getting along?

Probes: How would you describe your relationship with the baby?

Appropriate Questions for Later Interviews

How have things been going for you since we last met?

Probes: How have you been feeling?
What changes have occurred since we last talked?

How are things going between you and the baby?

Probes: Have you experienced any changes in your relationship with the baby?
Can you describe these changes?

How would you describe your relationship with the baby now?

How would you describe the baby?

Probes: How would you describe the baby's personality?
How would you describe the baby's physical appearance?
How do you know the description fits the baby?

How do you see the baby as part of the family?

Probes: How do family members interact with the baby?
How do you feel about the baby's relationships with family members?

What things have influenced your relationship with the baby?

Probes: What things have helped you to get to know your baby?
What things have hindered your getting to know your baby?
What others things can you identify which might have helped or hindered your relationship with the baby?

APPENDIX B

LETTER OF INTRODUCTION

LETTER OF INTRODUCTION

Dear ______:

I am a graduate student in the Faculty of Nursing, University of Alberta. I am interested in conducting research on the experience of being a mother of an infant with Down Syndrome. In particular, I am interested in learning about the mother's relationship with her infant during the infant's first few months of life. By learning about this experience from mothers like yourself, nurses will gain an understanding about mother-infant relationships which will assist them in providing care and support for other mothers with children with Down Syndrome.

I ask you to consider participating in the study. The study would involve approximately three interviews and the completion of one short questionnaire. The interviews could be conducted in your home and each interview would take approximately one hour. In addition, I would require that your infant be present during at least one of the interviews, in order that I am able to observe your interactions with the baby.

It is recognized that discussing this topic may be difficult for you. However, it is my belief that the information gained from mothers who participate in this study will ultimately be of help to other families in similar situations.

I would appreciate your consideration of this request. I will be contacting you by phone within the next week. At that time I would be pleased to give you more information about the study and to answer any questions you might have.

Sincerely,

Gail Diachuk

APPENDIX C

SAMPLE TELEPHONE STATEMENT

SAMPLE TELEPHONE STATEMENT

"Hello _______, this is Gail Diachuk from the Faculty of Nursing at the University of Alberta. You were given a letter by the social worker at the Edmonton Genetics Clinic concerning a study on mother's experiences following the birth of an infant with Down Syndrome."

"I am calling to see if you have any questions about the study and if you might be interested in participating in the study."

(At this time if the mother indicates an interest I would give her a brief overview of my background.)

"As was indicated in the letter, the purpose of the study is to learn about the experience of being a mother of an infant with Down Syndrome. In particular, I am interested in learning about the mother's relationship with her infant during the infant's first few months of life. This information will help nurses to better understand about mother-infant relationships which will assist them in providing care and support for other mothers with children with Down Syndrome."

"Do you have any questions at this time?"

(If questions are asked, then answers would be provided at this time.)

"I would like to set up a time that is convenient to meet with you. At that time I would ask that you sign a consent form to participate in the study. After you have completed the forms, I would like to interview you for approximately one hour. I would like to tape record the interview so that I can accurately document your feelings and thoughts. You will not be identified on the tapes and all information which is shared with me will be treated in a confidential manner. Further interviews will occur approximately 4-6 weeks after this first meeting. These arrangements will be made at a later date. At the time of the final interview, I will ask that you complete a short questionnaire."

Do you have any further questions?

(I would then confirm the time, date and place for the interview.)

APPENDIX D

INFORMED CONSENT FORM

UNIVERSITY OF ALBERTA: FACULTY OF NURSING

INFORMED CONSENT FORM

PROJECT TITLE: Maternal Attachment to the Infant with Down Syndrome

SUPERVISOR: Dr. P. A. Field INVESTIGATOR: Gail Diachuk

Phone: Phone:

The purpose of this research project is to increase nurses' understanding of the process of maternal-infant attachment following the birth of an infant with Down Syndrome. Two to three interviews will be conducted and each interview will last approximately one hour. During these interviews, questions will be asked regarding your experience of developing a relationship with your child. The interviews will be tape recorded and transcribed. To protect your privacy, you will not be identified on tape and the tapes and transcripts will be coded and kept in a locked cabinet until the end of the study. After this period of time the tapes will be destroyed and the transcripts will be kept in the locked cabinet for no longer than five years at which time they too will be destroyed. The final report will contain anonymous quotations and will be available at the end of the study.

There may be no direct benefits to the participants of this study, but there may be changes in the health care provided to families with Down Syndrome children following the completion of this study. In the event that child abuse is suspected, the researcher will discuss her concerns with the mother. In such cases as mothers with concerns about their infant or mother's who have difficulty relating to the child, the option of referral to the public health nurse or social worker will be made to the mother. However, the researcher has a legal responsibility to inform social services of cases of evident child abuse or neglect.

CONSENT FORM

THIS IS TO CERTIFY THAT I, ---------------------------------
(print name)

HEREBY agree to participate as a volunteer in the above named project.

-I understand that there will be no health risks to me or my child resulting from my participation in the research.

-I hereby give permission to be interviewed and for these interviews to be tape-recorded. I understand that, the tapes and transcripts will be kept in a locked cabinet. At the completion of the research, the tapes will be erased and that the transcriptions will be destroyed after five years. I understand that the information may be published, but my name will not be associated with the research.

-I hereby agree to have my child present during at least one interview, in order that the researcher observe the interactions between myself and my child.

-I hereby agree to complete a short questionnaire at the time of the final interview.

-I understand that I am free to deny any answer to specific questions during the interviews. I also understand that I am free to withdraw my consent and terminate my participation at any time, without consequences to myself or my infant.

-I have been given the opportunity to ask whatever questions I desire, and all such questions have been answered to my satisfaction.

-I understand that if at anytime information is disclosed to the researcher that identifies a threat to the health of my infant this will be discussed with me. Due to legal responsibilities, this information may need to be disclosed to other health professionals and may not be able to be treated confidentially.

---------------------	-------------------	----------------
Participant	Witness	Researcher

Date --------------