ED 385 972 EC 304 166

AUTHOR	Kalland, Mirjam
TITLE	Psychosocial Aspects of Cleft Lip and Palate: Implications for Parental Education. Research Report 138.
INSTITUTION	Helsinki Univ., (Finland). Dept. of Teacher Education.
REPORT NO	ISBN-951-45-6924-5; ISSN-0359-4203
PUB DATE	95
NOTE	218p.; Academic Dissertation, University of Helsinki.
AVAILABLE FROM	Department of Teacher Education, P.O. Box 38 (Ratakatu 6A), FIN-00014, University of Helsinki, Finland.
PUB TYPE	Reports - Research/Technical (143) -- Dissertations/Theses - Doctoral Dissertations (041))
EDRS PRICE	MF01/PC09 Plus Postage.
DESCRIPTORS	Affective Behavior; *Attachment Behavior; *Cleft Palate; Emotional Development; *Emotional Response; Foreign Countries; *Infants; Interviews; *Mothers; *Parent Child Relationship
IDENTIFIERS	Finland

ABSTRACT

This study focused on the psychosocial aspects of cleft lip and/or palate on maternal emotional reactions and the family, with emphasis on the effect on the maternal-infant bond. Interviews were conducted with 40 mothers of 1-year-old infants with non-syndromic cleft lip and/or palate. The interviews were analyzed using the phenomenological method, which is explained. The focus was the unique interpretation of the mothers' experiences. The main result was that a defect that interfered with feeding disturbed the early maternal-infant bonding process more than a defect that only interfered with the child's appearance. Additional findings include: the birth of a child with a cleft is considered a shock by most mothers; the most severe problem has been the feeding problem; surgery, even if desired, is considered as a shock by most of the mothers; feelings of depression, fear, or bitterness are common among mothers of infants with a cleft; and the information that the mothers received at the hospital when the baby was born was inadequate. Descriptions are included for three cases involving different types of cleft: cleft palate, cleft lip, and cleft lip and palate. Implications for parent education are discussed, such as the importance of providing parental support to facilitate successful parenting, parents' need for information, and the importance of contact and a sense of community. (Contains 209 references.) (SW)

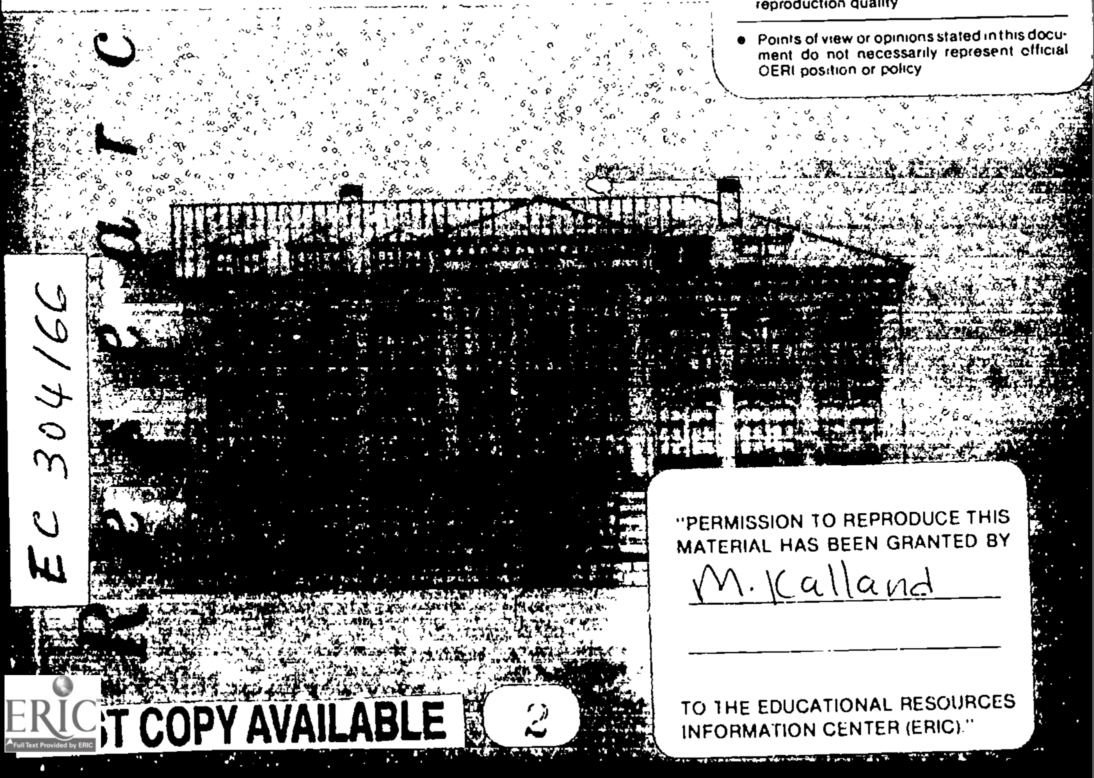
Research Report

Mirjam Kalland

PSYCHOSOCIAL ASPECTS OF CLEFT LIP AND PALATE

Implications for Parental Education

Department of Teacher Education
University of Helsinki



Available from:
Department of Teacher Education
P. O. Box 38 (Ratakatu 6 A)
FIN - 00014 University of Helsinki
Tel. 191 8112
Int. tel. +358 0 191 8112
Telefax +358 0 191 8114

Research Report 138

Mirjam Kalland

PSYCHOSOCIAL ASPECTS OF CLEFT LIP AND PALATE

Implications for Parental Education

Academic dissertation to be publicly discussed by due permission
of the Faculty of Education in the University of Helsinki,
in Auditorium I of the Department of Teacher Education,
on the 24th of February, 1995, at 12 o'clock.

Helsinki 1995

ISBN 951-45-6924-5
ISSN 0359-4203
Yliopistopaino
1995

To my children

University of Helsinki
Faculty of Education
Department of Teacher Education

Psychosocial Aspects of Cleft Lip and Palate: Implications for Parental Education

by Mirjam Kalland

Abstract

This study focused on the psychosocial aspects of clefting, with the main emphases on maternal emotional reactions and reactions in the family. The main objective of the study was to find out how the cleft lip and/or palate problem affects the maternal-infant bonding process and to find implications for parental education. At the outset, the questions that were formulated related to the tension between the (clinical) severity of the cleft and how the mother experienced the cleft. The empirical material was produced by interviewing 40 mothers of one-year-old infants with non-syndromic cleft lip and/or palate using an informal, conversational interview approach. The interviews were analyzed by using the phenomenological method.

The mothers experienced the birth of a baby with a cleft more or less as a disapointment. Some mothers reported severe difficulties to bond with their infants in the beginning, while others did not report such difficulties. A majority of the mothers expressed the need for more information about the cleft palate problem. However, the visual defect connected with the cleft lip was easier to overcome than the feeding problems connected with the cleft palate. Thus, the main result found in this study, was that a defect that interfered with feeding disturbed the early maternal-infant bonding process more than a defect that only interfered with the child's appearance. This result was interpreted thus: a visual malformation represented a mechanical problem that the mothers were able to overcome, while problems with feeding and eating represented a dynamical problem, since it interfered with the interaction process between the mother and her child.

In conclusion, problems with feeding deserve attention in order to facilitate the bonding process between the mother and her infant. Supportive programs addressing parents of new-borns with a cleft lip and/or palate have been created, including initial information in the delivery ward and adaptation courses.

Keywords: psychosocial, cleft lip and palate, maternal-infant bonding, parental education, phenomenology

Available from: Department of Teacher Education
PL 38 (Ratakatu 6 A)
00014 University of Helsinki

ACKNOWLEDGEMENTS

It goes without saying that a work like this could not have been brought to its end without the support of many people. My first thanks goes to the personnel at The Cleft Palate Center for giving me the opportunity to use their patients for my study. Their interest in my study has been very important for me. I would also like to thank the mothers that took part in this study: it could not have been possible without their participation.

A warm and deeply felt thanks to Associate Professor Ilse Eriksson-Stjemberg. She was always available for encouraging and stimulating discussions. Her interest and supportive attitude have been very helpfull for me. My heartfelt thanks to Professor Jarkko Hautamäki, who has shown a deep interest in my work and has given me much good advice. I also thank Associate Professor Airi Hautamäki for her valuable suggestions and genuine interest in my work. Thank to Professor Erkki A. Niskanen, who has shown his interest in my work by offering me valuable comments. Sincere thanks goes to Dean Veijo Meisalo, to Professor Pertti Kansanen and to Assistant Professor Juhani Hytönen for their support.

I am grateful to my friends and collegues Sinikka Maliniemi-Piispanen and Nina Santavirta for their never-ending enthusiasm: it has been very encouraging. I would also like to thank my students at the Department of Education: their critical questions have helped me to clarify my thoughts.

Special gratitude is extended to Ms Heidi af Hällström, who helped me to transcribe the interviews and to Paul Service and Margaritha Bosas who translated the interviews from Finnish and Swedish into English. A warm thank goes to Pearl Lönnfors, M.A., who kindly revised the English language in my thesis.

The financial support extended by the Oskar Öflund Foundation, the Finnish Association of Public Health and the Department of Education is gratefully acknowledged.

Finally, I offer my deepest gratitude to my family, who has handeled a sometimes somewhat absent-minded wife and mother with serene calm and a lot of patience.

My husband Jan Salvén, edited the figures and tables and provided me with practical help whenever it was needed. My children Martina and Annina (seven and six years old at the moment) have also contributed to this work in many ways. When Martina heard that I was writing a book about mothers and babies, she said: "You have to write that mothers love their babies". And so I did.

Helsinki

January 1995

Mirjam Kalland

CONTENTS

PART ONE: INTRODUCTION

PART TWO: EPOCHÉ

PART ONE: INTRODUCTION

1. THE CLEFT PALATE PROBLEM

1.1 Psychosocial Aspects of Cleft and Education

Anticipating the birth of a baby is always an exciting event, though there may be mixed feelings The majority of expectant parents are believed to have some anxieties during the period of pregnancy over the possibility that the baby may not be normal in some way. During the pregnancy the parents also develop a mental picture of the baby. an idea of the sex, eye color and so forth. This mental picture is a composite of the impressions and desires of the parents.

But the child is not visualized as a child with a defect or a handicap. An early task of parenting, especially when the infant has a defect, is to resolve the discrepancy between the mental picture of the infant and the actual picture of the infant. (Irvin, Kennel & Klaus 1976, 169.) This may be very difficult if the child has a facial malformation. A possible (and one of the most common) facial malformation is a facial cleft.

The birth of an infant with a cleft is considered a shock by most families. However, parental reactions to a malformed infant are not only due to the personality of the parents, but have to be seen in a sociological and historical context. Earlier in history infanticide was a cruel and primitive way for Westerners to deal with birth defects, and facial clefts have been described as the basis of infanticide. Today, a physical handicap may result in malnutrition of the child, as has been described in African case studies (Strauss & Broder 1990, 833 - 834, as reported by Oluwasanmni & Adelunkle 1970). Many traditional people distinguish between "killing" an infant and "allowing it to die." Thus one Mexican woman responded negatively to a question of whether children with cleft palate were killed. But she said, "Sometimes they can't eat with a cleft lip", and then after a small pause, she added, "and sometimes they don't give them anything to eat" (Scheper-Hughes 1990, 30 as reported by Mull & Mull 1987).

In developed nations the combination of economic resources and professional manpower have resulted in wide acceptance of the multidisciplinary team-based model for cleft palate care. At the same time there has been a transition from "infanticide tolerant" societies to "infanticide intolerant" societies. However, this does not mean that the problems connected with the birth of an infant with a facial cleft have disappeared.

Ortiz-Monasterio (1975) has indicated a need for public education about cleft palate: "Educating the public is quite important. Deformities are viewed more rationally when they are properly explained, and when the possibilities for treatment are outlined".

In the USA the American Cleft Palate Educational Foundation was established in 1973. The Foundation publishes educational material and provides information for the public, parents and patients (Middleton et al. 1986, 58).

In Finland, the first documented surgical repair of a cleft lip was made as early as in 1763, when Gerhard Odenadt from Turku repaired Thomas Ragwaldinpoika's (Ragwaldson) cleft lip (Rintala 1975, Rintala 1976) and several surgeries were reported during the 19th century. But until 1985 it was the Finnish Red Cross that took care of cleft patients in Finland. No public education material has been published, and parents and patients have been provided with a minimum of information.

The importance of parental education when a newborn baby is sick or malformed has been pointed out by many researchers: in fact it would be difficult today to find an educator who did not claim parents are important for the optimal development of disabled children (Ferguson & Ferguson 1987, 347). Philip Coombs distinguishes between nonformal and informal education. He defines nonformal education as any organized educational activity, outside the established formal system, that is intended to serve identifiable learning clientels and learning objectives. According to Coombs, informal education is a truly lifelong process that includes educative influences from family and neighbors, from work, play and the mass media. (Harman & Brim 1980, 16.)

According to this definition, parental education is nonformal education: parents are the primary clientel, and parental education is characterized as an organized, planned effort with a clear notion of aims and content. Since parents are adults, parental education is a form of adult education (ibid 16-18).

The ability to be a successful parent to one's children is influenced by many factors. One of the aims of parental education for families with special needs is to provide information about the child; another aim is to provide a possibility for the parents to meet other parents in the same situation. The formulation of programs is based on two premises: 1. Parents do have a significant effect on their children and 2. Adressing parents through educational activities promises a potentially high return. The ultimate goal of parental education is to have a beneficial impact on children, to assist in their growth and development. (Harman & Brim 1980, 23.)

The first premis, that parents have a significant effect on their children, corresponds with the view of Bronfenbrenner. Bronfenbrenner, who has studied childrearing practises in different countries, states that the best way to have an impact on children is to involve the whole family in the supporting programs (Bronfenbrenner 1975, 347; Bronfenbrenner 1981, 176). Bronfenbrenner also states that we already have the necessary knowledge about how to improve the capability and skills of the next generation (1981, 161): to support the mothers of infants. He also shares this view with other authorities in education and psychology, among them Bettelheim (1970 and 1989) and Fraiberg (1990).

Bronfenberenner also builds a bridge between theory and practice, between research and social politics. He studies problems of current interest, and in his publications he often makes appeals. He has also been called the "defence counsel of the children" (Lüscher 1981, 15).

This study is based on the premis that supporting the mothers of infants with the cleft palate problem will have a beneficial impact on these children, by giving the children a possiblity for a good start. The angle in this study is then educational. However, in order to be able to create supporting educational programs for parents, we must learn to know the *psychosocial* dynamics of clefting.

The concept *psychological* aspects of clefting often refers to studies of intelligence, self-image, personality and the psychopathology of cleft patients (McWilliams 1982, 317), while the concept *psychosocial* aspects of clefting refers to studies of parental emotional and behavioral reactions (Rogers, Barden & Kuzai 1990, 837).

Studies of parental reactions to the birth of a malformed or disabled child are often carried out in the area of special education. Dianne M. Ferguson and Philip L. Ferguson (1987) have created an organizational model of different approaches to parental reactions to a malformed or disabled child. According to them, there are two important questions that most research on parental attitudes and behaviors attempts to answer:

1. What is the nature of parental reaction?
2. What is the source of parental reaction?

The *nature* of parental reaction is perceived in predominantly attitudinal or behavioral terms, and the *source* is either normative or situational. The attitudinal approach tends to focus on what parents feel, while the behavioral approach tends to focus on what parents do. The normative answer to the source question is that, as a rule, the disabled child is the source of impaired parental behavior or emotion. The situational answer to the source question finds much less that is unavoidable in parental responses: the responses vary from situation to situation. According to Ferguson & Ferguson, this approach is still a minority position.

		Source of parental adjustment to a handicapped child	
		Normative disruption	Situational disruption
Nature of parental adjustment to a handicapped child	Attitudes	Psychodynamic	Psychosocial
	Behaviors	Functionalist	Interactionist

Figure 1. Nature and source of parental adjustment to a handicapped child (Ferguson & Ferguson 1987, 357)

These four dimensions can be combined with each other in a diagram that gives four possible research positions: the psychodynamic, the psychosocial, the functionalist and the interactionist.

The main interest of this study is in psychosocial aspects of clefting. According to Figure 1, this position focuses on parents' emotional reactions to having a malformed child. The source of these emotions is seen as largely determined by the social context rather than the malformation itself. However, this study did not begin with a fixed position about the nature and source of parental reaction. Therefore, the use here of the concept "psychosocial" refers rather to the focus of interest of the study than to a theoretical orientation.

The psychosocial factors have been divided into three groups (Bäckman 1993, 57): 1. The internal resources of a person (such as personality and the capacity to deal with different situations), 2. The external relations (family, friends etc.) and 3. structural relations, such as social systems in the surrounding society.

This study focuses on the psychosocial aspects of clefting, with the main emphases on maternal emotional reactions (group 1 as described above), reactions in the family and among friends and relatives (group 2), and the support the mothers felt that they got from the maternity hospital and the advice bureau for maternal care (group 3). However, these aspects of clefting are studied in order to find implications for parental education and possibilities for intervention. In summary, the *focus* of the study is on the psychosocial aspects of clefting, the *angle* is educational and the *aim* is to have an impact on social supporting systems, including creating supportive educational programs for the parents. But before returning to this aspect of cleft, a brief presentation of the cleft lip and/or palate problem is needed.

1.2 The Cleft Lip and/or Palate Problem

Cleft lip and/or palate is a congenital defect that occurs approximately once in every 500 births in Finland. Cleft occurs among all races and in both females and males, but clefts are more common in European and Asian populations than among the Black population (Charrow 1990, 20).

When discussing clefting, it is important to distinguish between solitary clefts and clefts associated with other birth defects or syndromes. Facial clefts have been identified as a part of over 250 syndromes, and the estimation of "syndromic clefts" in a cleft population vary a lot in different studies. In Finland, the estimation of clefts associated with other birth defects or syndromes account for 27 % for cleft palate, 10% for cleft lip and 28% for cleft lip and palate (Ritvanen 1994.) The use of the term "cleft palate child" has been considered incorrect, since it implies homogenety in the population. (Charrow 1990, 21 - 22; Goldberg 1990, 125; Lilius 1992, 8.)

This study concentrates on the psychosocial aspects of clefting among mothers of children with a solitary cleft that is not a part of a syndrome or related to another birth defect, in other words, the children in this study have no other problems in addition to the cleft palate problem. Despite the fact that an isolated cleft lip (CL) and a cleft lip accompanied by a cleft palate (CLP) are etiologically-related and could be considered as one group, CL and CLP are discussed as separate disorders in this study, for reasons that will be discussed in some detail later in the chapter. Thus, three different groups of facial clefts will be dealt with separately in this study: Cleft palate only (CPO), cleft lip (CL) and cleft lip and palate (CLP).

Clefts of the lip may occur on one side, a unilateral cleft lip (fig. 2a), or on both sides, a bilateral cleft lip (fig. 2c), with varying degrees of severity. The separation of the two sides of the lip often (but not always) includes the bones of the maxilla. A cleft palate can also vary in severity, involving either the hard palate or the soft palate or both.

Figure 2a. A child with a unilateral cleft lip and palate

Figure 2b. The same child at about three years of age

Figure 2c. A child with a bilateral cleft lip and palate

Figure 2d. The same child a few days after surgery

Cause of Cleft Lip and/or Palate

Despite the lack of clear agreement on the cause of clefts, it is generally thought that both genetic and enviromental factors are involved in the etiology of solitary non-syndromic clefts. Support for the hypothesis that oral clefts are not solely caused by genetic factors is found in twin studies: the proportion of affected monozygotic co-twins of patients with a cleft is reported to be about 30 to 50 % (Felix-Schollaart 1989, 13).

Clefting occurs very early in pregnancy (CL between weeks 4 and 7 of pregnancy and CPO between weeks 7 - 9 of pregnancy for the hard palate and weeks 10 -12 of pregnancy for the soft palate) and represents a problem over which a pregnant woman has little control (Rintala et al. 1986, 7; Eliason 1990, 825). However, finding associations between enviromental factors and oral clefts would make prevention a possibility, at least to a certain degree.

Three categories of environmental factors (from outside the mother) related to oral clefts are distinguished: physical agents, such as radiation, chemicals, such as certain medicines and vitamins, and micro-organisms. It is obvious that conservatism in using drugs and medicines during pregnancy is essential. However, enviromental factors can be numerous, and avoiding drugs during pregnancy is not a guarantee aginst a child born with a cleft. (Felix-Schollaart 1989, 16-18.)

Surgical Repair of the Cleft

The most important goal of palate surgery is to close the cleft so that the palate can function normally during eating and drinking and to ensure normal speech production. The goal of lip surgery is to close the cleft so that scarring will be minimal and the face will develop normally.

In Finland surgeries mainly take place at the Cleft Center, Helsinki University Central Hospital, in Helsinki. The reconstruction is done as teamwork by specialists from many different areas: plastic surgery, dentistry, audiology, speech and language pathology, and social work.

The initial surgical repair of the cleft is usually scheduled around the first year, depending on the type and severity of the cleft. Thus, the first surgical closure of the lip is usually scheduled at about two months of age, while the palatal closure is scheduled at about nine to twelve months of age. The total number of surgeries for a child with a cleft may vary between one to four times during the first year of life, but additional surgery is very likely to be necessary as the child grows. Final surgery is often postponed until the teen years when the face has reached full growth. (Rintala et al. 1986; Lynch 1989.)

Initial Difficulties

The first and primary problem for the parents when the newborn baby has a cleft might be of a psychosocial nature. The psychosocial aspects of cleft, which is the main topic of this study, will however be discussed later in Part Two. Here the focus is on what could be called "technical problems" connected with a newborn baby with a cleft (these technical problems can indeed create psychosocial and psychological problems, and vice versa, so the distinction is not necessarily correct).

Among the inital difficulties that have to be solved are feeding difficulties. Babies with clefts do not differ from normal infants in mean birth weight (in Finland they have a slightly lower mean birth weight than normal children according to Lilius (1992), but they do lag behind thereafter (Jones 1988, 382; Seth & McWilliams 1988, 146). One of the reasons for the low weight-gain per week is reported to be feeding difficulties (Jones 1988, 382).

Another problem connected with babies with clefts is respiratory infections, and respiratory infections are also reported to have a negative inluence on growth (both length and weight) (Felix-Schollart 1989, 92). These problems are the result of the inadequate function of some of the palatal muscles. In addition, children with a persistent middle ear disease are more likely to have some loss of hearing and this loss may affect speech development.

The articulation and resonance of infants with a cleft palate will be abnormal until palatal surgery is performed, but even after surgery there is an increased risk for some type of speech disorder.

Children with clefts also have special dental problems. Some teeth may be incorrectly shaped, out of correct position, or entirely missing. The inital dental treatment of cleft children is aimed at correcting extreme irregularities and crossbites and is scheduled differently for different types of problems.

1.3 The Cleft in a Context: An Adequate Problem

> "The term 'handicap' covers an enormous range of conditions. Some handicaps, such as the congenital absence of a finger or a toe, or a cleft palate, are so minimal or so easily corrected by surgery that they are hardly even noticeable, let alone disabling.... For this reason structural variation in the family resulting from a handicap can be traced only at the variant end of the continuum on which families with minimally handicappd children may not be distinguishable from other sorts of a family" (Rapoport et al. 1977, 117)

> "The conquest of the deformities that result from congenital malformation of cleft lip and palate is as dramatic a story as any in political or medical history. The potential problems that may beset the unfortunate victims of the condition include such severe handicaps as impaired suckling and resultant failure to thrive, speech impediment, deafness, malocclusion, gross facial deformities and severe psychological problems" (Stark 1990, v).

These two quotations, the first from a book on parenting, and the second from a book about cleft lip and palate, illustrate the diverisity between different attitudes towards clefting Rapoport et al seem to think that a cleft palate is comparable with a missing toe, whereas Stark describes the cleft palate problem as a potentially severe one. In this study, the cleft palate problem is considered to be a potentially severe one, but a problem in which early intervention potentially has a good outcome.

From the 1950s to the present the psychological and psychosocial aspects of clefting in children have been the center of attention. There are several reasons for this interest, for example the relatively high frequency with which clefting occurs (Lavigne & Wills 1990, 37). In fact, in Finland, clefting is the one of the most common single birth defects (approximately 130 per year) (Child Welfare 1993, 27).

In addition, the radical effects that a cleft can have on a child's appearance and feeding difficulties are quite striking. These effects are sources of stress for parents and might therefore constitute developmental obstacles for the child as well (McWilliams 1982, 317; Rosenstein & Schulman 1990, 47). It has also been suggested that the reactions, feelings and attitudes of parents of malformed children are even more important to the child's mental and emo- tional health than the impact of the deformity itself (Macgregor 1982, 286).

How successfully the family adapts to the situation depends on several different factors, such as the personality of the parents, the severity of the cleft and so forth. But there is increasing evidence that some of the early maternal-infant interaction problems could be reduced by instituting aggressive newborn outreach and education programs: In one study educational and emotional support within the first 24 to 48 hours after the birth of affected infants indicated a reduced rate of failure to thrive. Parents also reported feeling less overwhelmed by the birth defect and better prepared to cope with the emotional strains of repeated hospitalizations and surgeries (Rogers, Barden & Kuzai 1990, 837). The importance of providing accurate information to parents about the cleft palate problem on a more general level has also been pointed out (Paynter, Edmonson & Jordan 1991).

A child with a cleft palate is also known to have an increased risk for both articulation and communication disorders (Haapanen 1992, Haapanen 1993, 15; Öfverlund 1993, 311) It has also been shown that cleft palate infants differ from normal infants in their communication skills when interacting with their mothers, and that the mothers seemed to use less language facilitating aspects as compared to the mothers of normal born children (Koopmans-van Beinum et al. 1988, 38). Field and Vega-Lahr (1984) have noted that mothers of cleft lip and palate infants tend to engage in less frequent smiling, vocalizing, imitative behavior, and game playing with their infants than mothers of normal infants, and they also tend to be unaware of their unnuturant behavior. Since maternal warmth, responsiveness and speech to the child seems to be of great help in language acquisition - the structure of vocal communicative exchanges between mother and child at 3 months of age correlates with language acquisition at 2 years of age - this is one possible explanation of the fact that children with cleft lip and palate run an increased risk of having some type of language disorder. (Freedle & Lewis 1977, 182; Kristiansen 1992, 77; Olim 1975, 309.)

On the other hand, a recent study by Chapman & Hardin (1991) indicates that there are more similarities than differences in the maternal language characteristics of two groups of mothers: mother - cleft lip and palate child dyads and mother - noncleft child dyads. In this study, the youngest children were 12 months and the oldest 3 years, whereas Field and Vega-Lahr observed 3-month-old infants. Thus mothers of children with cleft lip and palate might be less responsive initially, but demonstrate more positive patterns of interaction gradually, when accepting the cleft condition better (Chapman & Hardin 1991, 83).

The birth of an "imperfect child" has also been placed in the context of a narcissistic injury: the mother feels that she has failed in becoming the "dream-mother of a dream-child" (Gustavsson 1989; Hautamäki 1993, 17). Of particular importance for this study is the report that mothers who experience the most severe sense of narcissistic injury were those whose children had defects that interferred with feeding, eye contact or smiling (Belfer et al. 1982, 310).

A parent's perception of his child as having positive bodily attributes gives to the child an opportunity to become comfortable with himself as he is. Failure in this process may lead to the development of pathologic-psychological defenses (Belfer et al. 1982, 309) The psychosocial adjustment of children with facial deformities has been studied, and the studies indicate that these patients function less well than healthy comparisons, and some researchers suggest that children having craniofacial surgery should have supportive psychotherapeutic services (Pillemer & Cook 1989, 202; Leonard et al. 1991, 347; Padwa, Ewans & Pillemer 1991, 356; Kapp-Simon K., Simon D. & Kristovich 1992, 352). According to one study (Noar 1991) parents are generally satisfied with their children's appearance and speech, but they feel that their children are socially and emotionally affected by their cleft.

1.4 The Purpose of the Study

As already mentioned, the focus of this study is on psychosocial aspects of clefting, with the main emphases on maternal emotional reactions. The overall purpose of this study is to learn to know how the cleft problem influences the bonding process between the mother and her child (bonding refers here to the tie between the mother and her child, whereas attachment refers to the tie between the child and his mother). The main idea is to learn to know the personal interpretation each mother has made of the event (the birth of a child with a cleft lip/and or palate) and the quality and quantity of the problems that have occurred during the first year with the new member of the family. This purpose can be formulated in three questions:

1. Is the mother's experience of the cleft of her child directly proportional with the severity of the cleft? or
2. Is the mother's experience of the cleft associated with the *apprehension* of the severity of the cleft problem she got when the baby was born? and
3. Which of the typical problems connected with the cleft, the visual and the functional problem, is apprehended as more difficult to accept by the mothers?

These three questions together actually form a typical phenomenological approach to ask how people apprehend a problem in relation to the severity of that problem (Edfeldt 1976, 8), and what the factors are that influence peoples' apprehension of certain problems or phenomena.

Another purpose of this study is to find possibilities for intervention. Therefore, the focus is on the first information the parents received at the hospital, the education they got about how to feed their infant and the emotional support they have received from official supporting systems and social networks.

In Finland, becoming a parent of a child with a handicap has received fairly good attention (see for example Määttä 1981; Räsänen & Väätänen 1986; Hautamäki 1993). However, the psychosocial aspects of cleft lip and palate have received little attention so far, and as a consequence no data has been gathered on what type of information the families are given at the time of the birth. Since the researcher herself has a child with a unilateral cleft lip and palate (now 6 years old), one of the hypotheses was that the information given was not enough or even adequate and that the emotional support given was minimal. In consequence, efforts were made to start supporting programs for families with children born with cleft deformities. This process has run parallel with this study. Thus, besides the two main purposes, a third purpose can be mentioned: to have an impact on official supporting systems, in other words, to use the results to develop the first information in the delivery wards and through adaptation courses for the families.

As mentioned earlier in this chapter, clefts are divided into three different groups in this study: Cleft lip (CL), cleft lip and palate (CLP) and cleft palate only (CPO) The reason for this is that these groups are considered to represent different types of initial problems. Thus the CL represents problems with appearance (mainly), CLP represents functional problems (feeding, speech and respiratory infections) and problems with appearance, while CPO represents functional problems (mainly). All these are given equal attention in this study.

2. METHOD AND MATERIAL

In this study the central focus is on the unique interpretation of the experiences of the mothers. The unique interpretation people make of their experiences is also the central focus of phenomenological psychology (Spinelli 1989, xiv). This neither excludes the ethological nor the psychoanalytical approach, but it indicates a certain degree of doubtfulness towards rapid conclusions drawn from certain circumstances.

The emphasis on the unique interpretation, however, was not a preassumption when the study began. On the contrary, it was the result of the first interviews, that did not fit the underlying hypothesis of the study (see Part Two, Epoché). Thus, the empirical studies have had a strong impact on the selected theories, and vice versa, and the progress of the study has been a reciprocal process between theory and praxis.

In order to learn to know the unique interpretation each mother had made of the birth of a child with a cleft, interviewing was considered the best method. Several possible research designs were considered, for example a few mothers could have been interiewed several times during the first year. But in the "critical trade-offs" (Patton 1990, 167) of research designs, it is necessary to determine if it is desirable to study a few objects in great depth, or many objects, but in less depth.

This trade-off between breadth and depth is often considered to be the major trade-off between quantitative and qualitative methods (but this division of studies into qualitative versus quantitative is not necessarily the best possible division). But even when the decision is made in favor of so-called qualitative methods, the trade-off remains. Qualitative inquiry typically focuses in depth on relatively small samples, in fact even on single cases (where n=1). This single case can be interviewed for 30 hours, focusing on depth. On the other hand, one can interview 30 objects for one hour and get the same quantity of information, but now focusing on breadth. (Patton 1990, 165.)

if I had interviewed just a few mothers several times, the advantage would have been the possibility of following the stages of interpretation and changes of meanings. But since the interviews took place at the hospital after a surgical repair of the infant's cleft, this research design would have left out the cleft palate group (with only one surgical repair).

As every mother was interviewed just once, the sample became larger. Since psychosocial aspects of cleft have not been studied before in Finland, the possibility to interview as many mothers as possible (under conditions of limited resources) was considered an advantage. So the final decision can be said to have been made in favor of breadth.

2.1 Methodological Issues

The method in this study is one that is in harmony with the emphasis on the unique interpretation of our experiences: starting with a deep interest in hermeneutics and, once again because of the impact of the empirical studies, ending up in a growing interest in phenomenology. Hermeneutic inquiry has been said to always include its own metatheory (Engdal et al. 1977, 7), and the same can be said about phenomenology.

To speak of "phenomenology" is not to speak of a single, unified philosophy. Edmund Husserl is often mentioned as the primary "inventor" of phenomenology, but phenomenology can be identified as a manner or style of thinking that existed as a movement before arriving at awereness of itself as a philosophy. (Merleau-Ponty 1962, viii; Giddens 1976, 24.)

Phenomenology as a method claims to be a radical way of thinking. Martin Heidegger, one of the giants of the phenomenological movement, claims: "Only as phenomenology, is ontology possible" (Heidegger 1962, 60). But before returning to in which way phenomenology is radical as a method, it is important to make two things clear: firstly, it is not the aim of this study to give a full and satisfactory description of phenomenology as a philosophy. The main emphasis in this chapter is to describe the phenomenological method as described by Ihde and Spinelli.

Secondly, this study is not a pure phenomenological study. Phenomenology, in terms of phenomenologcial psychology and the phenomenological method, is the main framework of this study, but other theories will be used as well. Doing phenomenology is claimed to be the only way to understand phenomenology (Merleau-Ponty 1962, viii); thus one product of this study may be a deeper understanding of this movement.

Intentionality

When a method is radical and new, its concepts will to some degree be unfamiliar and strange. Husserl stretched the meanings of previous terms and used them in a new way. The term *intentionality* is used in a way that has its origin in Brentano's thinking. Thus, intentionality is the directional shape of experience. Husserl made a distinction between *what is experienced* and the *mode of being experienced*. For what is experienced, he used the term *noema*, and for the mode of experiencing, which is detected reflexivity, he used the term *noesis*. Noema refers then to the object (the what) that we direct our attention towards and focus on, when noesis refers to the mode (the how) through which we define an object. (Ihde 1986, 43, Husserl 1989, 25; Spinelli 1989, 13)

Essence and Existence

The phenomenological movement can be divided into two different major branches: The transcendental phenomenology, of which Husserl is the most prominent exponent, and existential phenomenology, which was principally influenced by Heidegger (Spinelli 1989, 3).

Transcendental phenomenology is the study of *essences*. Essence is a term which means a general character, that which a number of things have in common (for example the essence of perception). Phenomenology (after Husserl) is also a philosophy which puts essences back into existence (Merleau-Ponty 1962, vii), where each of us can be described as being-in-the-world, but at the same time each of us experiences being-in-the-world in a unique way (Spinelli 1989, 26).

Life-world

The phenomenological method is most often used in studies concerned with life-world experiences, not with laboratory set-ups. The life-world is characterized as being pre-given and taken for granted. This taken-for-grantedness can be called a natural, non-reflective attitude. Some experiences can break this attitude momentarily, and more dramatic experiences can change the life-world of a person permanently.

However, the concept life-world has not yet reached the level of thematic clarity. A distinction between the cultural life-world and the invariant structure of the life-world should be made. The cultural life-world changes over time and differs from one place to another. But even if the content of various life-worlds may differ from one another, they share a common invariant structure, something that every life-world must posess in order to be a life world: the spatio-temporal causal structure, the time and space we refer to in our everyday life (Karlsson 1993, 39).

2.2 Rules of the Phenomenological Method

One of the most important concepts to introduce in the phenomenological method is *epoché* (the term comes from Greek and refers to scepticism), and also to avoid expressing an opinion (Husserl 1989, 69). This means to step back from our ordinary ways of looking at things, from the natural attitude belonging to the life-world, to go back "to the things themselves".

Here it is important to make a distinction between the concepts phenomenological reduction, transcendental reduction and eidetic reduction. According to Juntunen (1986, 70-109), Husserl uses the concept "phenomenological reduction" only to mean "transcendental reduction", which is the same thing as epoché. This stage includes the bracketing of not only the expectations and assumptions of the researcher, but also the expectations and assumptions that are accepted more generally, expectations-in-common or transcendental expectations. This concept is thematic in phenomenology, and has never reached clearity in the philosophy of Husserl. Transcencental reduction is however a series of operations that starts with the *Cartesian doubt*. The aim is an apodictic base of science. This means that "everything that could be other than it is" has to be bracketed, as already mentioned (Juntunen 1986, 84). According to Juntunen, the Cartesian doubt is not just one way to carry out the transcendental reduction: on the contrary, there are several ways to carry out the reduction with the Cartesian doubt as a base.

Epoché includes both a negative and a positive dimension: a "reduction from" and a "reduction to". The negative dimension is the bracketing of the natural attitude, while the positive dimension is reduction to the eidos of a phenomena. When looking at the epoché this way, we can see that the eidetic reduction can be seen as the positive dimension of the epoché: according to Juntunen, the eidetic reduction is one variant of the positive aspect of the epoché (Juntunen 1986, 96.)

The purpose of eidetic reduction is to find the eidos of the phenomenon in study. The noema, the "what" we see, however, is not the same as eidos. For example, if we study the eidos of a cleft lip and palate, we will found that a mother can "see" a child with a cleft and she may also "see" a child that will not develop normally (whether it is a fact or not). However, the second thing that the mother "sees" does not belong to the eidos of a cleft, even if it belongs to her noema.

In fact, one noema may have several different "eidos", and the noema we study must not correspond with anything existing in reality. Thus it is possible to study the eidos of the noema "ghost". The problem with several eidos for one noema can be explained with the interest of knowledge the researcher has in the particular situation, and this interest is hidden in the noesis, the "how". (Juntunen 1986, 76)

If we now go back to the first distinction between phenomenological reduction, transcendental reduction, epoché and eidetic reduction, the conclusion here is that epoché has two dimensions: the "reduction from", and the "reduction to", which is eidetic reduction. The phenomenological reduction and the transcendental reduction must therefore be the same as epoché. According to Juntunen, this is also the way Husserl uses the term phenomenological reduction (Juntunen 1986, 70). This can be illustrated by the following figure:

EPOCHÉ OR
PHENOMENOLOGICAL
REDUCTION OR are different names for the same process.
TRANSCENDENTAL This process can be divided into:
REDUCTION

1. negative reduction (reduction from)
2. positive reduction (=eidetic reduction)

Juntunen offers another solution. According to his use of the words, transcendental reduction and epoché are the same thing, but phenomenological reduction is used as a standard name for all reductions connected with the phenomenological method. Phenomenological reduction is then a non-specific name that can refer to different processes, such as epoché or eidetic reduction.

EPOCHÉ OR are names for the same process.
TRANSCENDENTAL This process can be divided into:
REDUCTION

1. negative reducion
2. positive reduction (=eidetic reduction)

The point is, however, that epoché is a coin with two sides, and that eidetic reduction is the positive reduction-to-side of this coin. Husserl expresses this in his work *Die Idee der Phänomenologie*: "Even if epoché must begin with questioning all the knowledge, it cannot be its idea to stop there..." (Husserl 1989, 69). Since the use of the concepts phenomenological and transcendental reduction are varying a lot, and since Husserl's use of the concept epoché seems to be quite clear, I prefer to use the concept epoché further on in this study.

Epoché can be achieved using several different techniques. The base is, as already mentioned, Cartesian scepticism. Ihde offers a technique in four steps.

The first rule is *bracketing* our expectations and preassumptions (both theoretical and natural), so that we can focus on the primary data of our experience. Here we shift from a natural to a phenomenological attitude (Ihde 1986). To bracket a theory does not mean to repress or deny it. Karlsson (1993) describes the process of bracketing in this way: "It means to bring the theory to a thematic level in order to be authentically capable of setting it aside" (Karlsson 1993, 82).

The second rule is *the rule of description*: Describe, don't explain. Explanation is exluded in this intial phase, because early explanations may lead to misinterpretations. By explanations we try to go behind phenomena, to seek reasons, and this may be an obstacle for attending to phenomena as they appear (in hermeneutic language, our pre-understanding may be blocked, but to this I will return later in this chapter) (Ihde 1986; Spinelli 1989). This descriptional stage has also been described as naive description, which means that catergories of analysis or explanation do not enter the initial description (Giorgi 1985b, 43).

The third rule is that of *horizontalization*. This rule urges us to avoid placing any initial hierachies of importance upon the items of our descriptions: all phenomena must be thought of as "equally real" within the limits of their "givenness". This procedure prevents one from deciding too quickly that some things are more fundamental than other things. (Ihde 1986; Spinelli 1989.)

The fourth rule, and now we are coming to what the essence of the phenomenological method is: seek out structural or invariant features of the phenomenon. This means that repeated patterns are significant and must be probed (Ihde 1986, 39). This fourth stage gives a possibility for the eidetic reduction that was described above. This fourth rule is sometimes left out in descriptions of the phenomenological method (see Spinelli 1989, 18). Other theorists, such as Giorgi (1985) and Karlsson (1993), have developed slightly different outlines of the phenomenological method. However, different descriptions of the phenomenological method have crucial elements in common: the emphasis on (naive) description, the reduction (including negative and positive reduction) and the search for essences.

The first rule, the rule of bracketing, is the negative reduction. The next two rules are very typically epoché: with them we avoid "expressing an opinion". Since we are still "avoiding" and not yet capable of finding the eidos, these two steps must also belong to the stage of negative reduction. The last step is clearly the positive dimension of epoché, the eidetic reduction. Also this may be illustrated by a figure:

EPOCHÉ: 1. Negative reduction
  * bracketing
  * describing
  * horizontalizing

2. Positive reduction (eidetic reduction)
  * finding invariant features

We start with Cartesian skepticism. The aim is to find an apodictic base for science. The result is that we will find the eidos of a phenomenon.

The four rules above make up the phenomenological method. This method is the basis of this study, of the method of inquiry and, above all, this method is used when analyzing the matherial. These four rules give us the essence of the cleft palate problem. Later in this study this method will be presented step by step, stage by stage.

Another aim of this study is to find implications for parental education. Therefore, one more step will be included in this study: the essence will be put back into existence, in order to reach the meaning of the phenomena in study. This aspect is considered by Spiegelberger as an essential step in the phenomenological method, although often left out (Spiegelberg 1982, 678 - 715). Thus existential aspects of cleft will be examined and probed in Chapter 5, part II of this study.

But before that, it is essential to return to a more practical level, that is, the method used for gaining information regarding the essence of how mothers experience their infants who are born with a cleft.

2.3 Interviewing as a Method of Inquiry

The purpose of interviewing is to gain information of inner perspectives, "to find out what is in and on someone else's mind" (Patton 1990, 278). These inner perspectives cannot be directly observed. Therefore, the question is not whether direct observation would be more desirable or if measurable data would be more reliable. The fact of the matter is that we, by interviewing people, get access to the perspective of the person being interviewed, access that we would probably not get in any other way.

This does not, however, implicate that by interviewing people we automatically get access to their minds. The interview siuation offers only a possibility to get access to other people's inner perspective.

An interview may be defined as a joint product of what interviewees and interviewers talk about together, and how they talk to each other (Mishler 1986, vii). The interview is usually classified as either structured, semi-structured or unstructured on the one hand, or as more or less "deep". Patton (1990, 280) divides (qualitative) interviews into three different types:

1) the informal conversational interview
2) the general interview guide approach, and
3) the standardized open-ended interview

The first catergory, the informal conversational interview, can be considered to belong to the same category as Mishler's (1986) *narrative interviewing,* and it is this method that has been used in this study. This method allows the interviewer to maintain maximum flexiblility to individual differences and situational changes. The questions, though emerging from a special theme, will be asked differently each time, and interview questions will change with time. In this study the interviewee played the active part and the interviewer the passive part in the interview situation. This becomes clear when studying the transcribed interviews: one question or a short comment could result in several pages of talking.

The informal conversational interview is more open to interviewer effects, and it depends on the interactional skills of the interviewer to a greater extent than a standardized interview. Data obtained from this type of interview is also more difficult to pull together and analyze. (Patton 1990, 282.)

Patton classifies data obtained from informal conversational interviews as merely qualitative, while other theorists classify data of this type as being semi-qualitative (at its best) (Åkerberg 1986, 49). Åkerberg also suggests that in order to obtain data of a semi-qualitative level from an interview, there should not be only one meeting between the interviewer and the interviewee.

It is not, however, the aim of this study to be a contribution to the ongoing discussion among educational and other theorists about qualitative versus quantitative data (see for example Phillips, D. C. 1991; Ricoeur 1992). Data obtained from this study made it possible to gain information regarding the experiences of the mothers, and was thus satisfying.

Emphasis on Descriptive Questioning

In this study the emphasis was on descriptive questioning, focusing on what and how (that is, the noematic and noetic foci of intentionality). The questions rarely began with why, for reasons that had their origin in intuition on a practical level: "why" questions can imply (or confirm) that a person's reactions or responses are inappropriate.

This intuitional avoidance of asking "why" questions was later confirmed to be of a great importance, also on a more theoretical level (the second rule of the phenomenological method: Describe, don't explain); "why" presumes cause-effect relationships, and attempts to answer such questions would lead to speculations on both the interviewee's and the interviewer's part (Spinelli 1989, 131; Patton 1990, 313). Furthermore, in this study the cause-effect relation is not seen as the most adequate way to describe human experiences - at least not in the initial phase.

Rapport, Empathy and Neutrality

"I cannot be shocked, I cannot be angered, I cannot be
embarrassed, I cannot be saddened..."(Patton 1990, 317).

In order to establish rapport (here defined as a close relation) with a person, it is necessary for the interviewer to maintain both empathy with and neutrality towards the interviewees and their experiences. Neutrality means here that it is not the interviewer's task to value, to judge or criticize, nor to give any instructions. Through neutrality the interviewer is also more able to bracket his own interpretations of the world. Through empathy (here defined as emotional identification with somebody) the interviewer will be able to enter the interviewee's inner perspectives, but empathy must be based on understanding without judgment. (Spinelli 1989; Patton 1990)

This is certainly the most difficult task for the interviewer. It is not easy to listen to a mother, apparently insensitive to the needs of her child, without even trying to give her any advice. But it might be helpful to remember that advice or instructions seldom fulfill the needs of a mother in distress - but empathic listening might be very helpful (and is certainly a very rare experience for most people.) Shifting perspective from a noematic (what) to a noetic (how) might also be helpful: it is usually easier to identify with how a person felt, than with what a person did.

This neutrality does not mean that no intervention is possible: on the contrary, if an interviewee needs help, she will receive help. In this study such an intervention was made once, when the researcher after the interview situation offered help to a mother in an extremely difficult situation.

The main idea with establishing rapport in an interview situation is that when the interview is based on rapport, there is a possibility - for a moment - to bracket the "tacit agreement" on what is decent to talk about (Alasuutari 1993, 182).

Preunderstanding and Access

"Whilst Freud had a vast knowledge about anxiety, Kirkegaard knew anxiety" (Rollo May 1986)

To have knowledge about something or to know something are certainly two different things. These two kinds of knowledge can be described as knowledge by accquintance and knowledge by description. One implication of the difference between these two types of knowledge for an understanding of pedagogy is formulated by Pojman: Only what is learned by experience, personally appropriated, is truly known (Curtis 1978, xxi; Pojman 1978, 11). Pojman also refers to Kirkegaards' theory of subjectivity, in making a distinction between essential knowledge and accidental knowledge. Essential knowledge relates to one's personal existence, whereas accidental knowledge is related to the intellect alone (Pojman 1978, 8).

However, to experience something and to have knowledge about one' s experience are two different things. In order to get knowledge about one's experiences, one need to interpenetrate the experiences with reflection. According to Russell, we can finally gain knowledge that trancendence our experience. (Russell 1984, 1960.)

The preunderstanding of a problem develops from some kind of knowledge. Sometimes knowledge by acquaintance is preferable, in heuristic inquiry (a form of phenomenological inquiry) even a condition. When studying intense human experiences (not casual experiences), when concerned with meanings, not measurements, with essence, not appearance, with experience, not behavior - the personal experience and insights of the researcher are essential (Gummeson 1988, 53 - 64; Patton 1990, 71). Kirkegaard says: "All existential problems are passionate problems, for when existing is interpenetrated with reflection, it generates passion" (Kirkegaard in Pojman 1978, 6).

Especially if we wish to get access to the problem and rapport with the interviewee, knowledge by acquaintance is helpful. In this study the researcher had this type of knowledge, and this was told to the interviewees. The interviewees responded positively to this, stating that "Well, then I can talk to you, because you know these things".

This preunderstanding should not be blocked; despite the preunderstanding, a researcher should be unbiased and stay sensitive and responsive to contradictory evidence, maintain what Glaser & Strauss calls "theoretical sensitivity" (Glaser & Strauss 1967, 46; Glaser 1978; Yin 1984, 57; Strauss 1988). Or, as Gadamer expresses it: "Reflection on a given preunderstanding brings before me something that otherwise happens behind my back" (Gadamer 1977a, 38).

If we maintain theoretical sensitivity, the preunderstanding will step by step become deeper in a reciprocal process known as the hermeneutic circle (or spiral) (Andersson 1982, 149). In this process, also known (especially in a phenomenological context) as a dialectic of interpretation (Ihde 1986, 31), the part must be understood in the context of the whole and the whole must be understood as more than the sum of the parts. Understanding is thus an interplay between the movements of tradition and the interpret (Gadamer 1977b, 88 - 91).

Or, using everyday-language: "In order to find out, I must in some sense already know; but in order to know, I must find out" (Ihde 1986, 30).

2.4 The Progress of the Study

The study started in March 1991 and the last interview was made in September 1992. The interviews took place mainly at the The Cleft Center in Helsinki. At the time of the interview, the child was about one year of age (the youngest was 9 months and the oldest was 2 years, but these were exceptions) and the CLP and CPO children were going through palate surgery. The interview was not made before the surgery, but a few days after the surgery, when the mother already felt safe about the recovery of her child.

Of the mothers belonging to the CL-group, two were interviewed at the Cleft Center, one in another city in the south of Finland, one at her office, and four mothers were interviewed at my office at the University of Helsinki. As children with a cleft lip go through their only or main surgery at the age of six months, I had to contact these mothers in a different way, in order to interview them when their children were about one year of age. These mothers were finally contacted first by letter and then by telephone. No one refused to take part in the study.

Before the study I talked with mothers with children of different ages and with different types of clefts, and during the study there were also many "unofficial" contacts with mothers of children with clefts. These discussions were not included in the study, but they were a part of my preunderstanding (of course added to my own experiences).

Partly because of these discussions, I decided to interview mothers of one-year-old children. At that time the mothers had not yet forgotten the birth and the feelings they had experienced (and partly still had), and they were able to report the support they had recieved from the surrounding official and unofficial supporting systems. Their children had also gone through at least one surgery, and they had been forced to meet their own feelings towards their children before and after the surgery.

As sex and age have an impact when establishing rapport with a person in a research situation, and a woman is believed to make contact more easily with another woman than with a man (Repstad 1988, 52), the fathers were not interviewed. In this study it was of great importance to establish rapport with the interviewees, and this was one of the reasons for not interviewing the fathers.

Another reason for this was that if the fathers would have been interviewed, it would have been difficult to include 40 families (which is about one third of the total annual "cleft-population" in Finland) in this study: 80 interviews would have generated about 2000 pages of transcribed text. As mentioned before, since this is the first study of this kind in Finland, the possibility of including as many families as possible was considered to be an advantage.

Finally, the fathers do not always have the possiblity to stay with their families at the hospital. There may be other children in the familiy, and the fathers may take care of the siblings while the mother is at the hospital with the child with a cleft.

The Sample

The sampling method in this study may be called purposeful sampling (Patton 1990, 169). The logic and power of purposeful sampling lies in selecting information-rich cases, the study of which will illuminate the questions under study. Patton describes 15 different purposeful-sampling strategies (Patton 1990, 182 - 183).

The strategy in this study was purposeful random sampling, because the cases were chosen in terms of representing different types of clefts: CLP (cleft lip and palate), CP (cleft palate) and CL (cleft lip). A small purposeful random sampling does not permit statistical generalizations, and the purpose is credibility, not representativeness (Patton 1990, 180).

At the same time, the sampling method was criterion sampling: the cases had to meet some predetermined criteria. In this case, the child should have a solitary cleft that is not a part of a syndrome and no other confirmed disabilities (during the course of the study, additional problems were sometimes identified later).

Most of the mothers stayed with their infants at the hospital, but since not all of them did so, efforts were made to get in touch with mothers that did not stay with their infants. Thus, some of the interviews were not made at the hospital, but in my office at Helsinki University.

The contact with the mothers was sometimes established on a person-to-person basis and sometimes by telephone. Thus agreement on where and when the interview was going to take place was (usually) made one or a few of days before the actual interview. It was not particularly difficult to get this agreement as the mothers were eager to take part in the study. (Sometimes so eager that they waited outside the door where an interview was being held in order to get a chance to be interviewed.)

After the first interview, the mothers that were at the Cleft Palate Center knew that something was going on, and they apparently asked each other what questions had been asked. Sometimes they had some answers prepared in advance, but after a while they usually relaxed and started to talk in a free and open way.

The point of saturation (Glaser and Strauss 1967) (that is the point when the researcher gets the feeling that no new information will be gained by adding more cases to the sample) was achieved after about 35 cases, but a few more cases where added to be sure that this point of saturation was not only a point of exhaustion. A total of 40 mothers were interviewed, thus about 1/3 of the whole annual cleft-population in Finland (approximately 130 every year) and more than 40% of the non-syndromic cleft-population (approximately 95 every year) were included in this study (see Table 1).

	Cleft population and sample		
Cleft type	Incidence 1992	Sample in study	% of population 1992
CPO	48	16	33
CLP	26	16	62
CL	20	8	40
Total	**94**	**40**	**43**

Table 1. Solitary cleft population (Ritvanen 1994) and sample

The mothers represented Finland from West to East, and from a southern island in the archipelago to Lapland in the North. 27 (of 45) different maternity hospitals were represented.

The youngest mother was 20 and the oldest was 45, with a mean age of 30.7. The number of children varied from 1 to 5 with a mean of 2.1. The mothers' educational background varied from comprehensive school to higher academic professions.

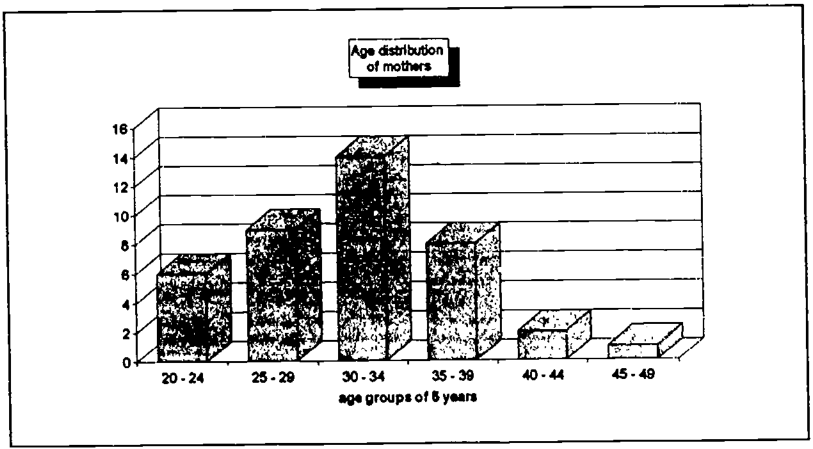


Table 2. Age distribution of mothers. n = 40

The cleft type varied in the following way:

Sex	*Cleft type* CPO	CLP	CL	Total
Boy	5	13	6	**24**
Girl	11	3	2	**16**
Total	**16**	**16**	**8**	**40**

Table 3. Cleft type and sex. n = 40

The birth-order was also of interest in this study, as it is often indicated that the birth-order of children may have an impact on parental reactions.

	Cleft type CPO		CLP		CL		ALL
Birth-order	Boy	Girl	Boy	Girl	Boy	Girl	
1	1	3	4	1	2	-	**11**
2 +	4	8	9	2	4	2	**29**
Total	**5**	**11**	**13**	**3**	**6**	**2**	**40**

Table 4. Cleft type, sex and birth-order. n = 40

The Hospital

The Cleft Center, Helsinki University Central Hospital, at the time of the study, was situated on the fifth floor in an old hospital building (the rest of the hospital is a private hospital, but the Helsinki University Hospital rents the fifth floor for the Cleft Center). It is situated in the center of Helsinki.

The rooms were small, old-fashioned and not very comfortable and the equipment was minimal. The staff and the Cleft Palate Association in Finland had bought new curtains and painted the walls in order to make the rooms look a bit nicer, but the impression might still have been depressing when seen for the first time: A long, narrow passage with closed doors on both sides. There was from two to four beds with iron sides in the childrens rooms, and one table and two small chairs. Children's hands were tied up to the sides in order to prevent them from touching their sores, and this sight may also have been difficult for the parents to get used to.

One mother said the following about the hospital:

"I was warned that this is a depressing place ... I was used to these new ones (hospitals) and then when we came here there was a rusty bathtub from the 40s... (laughing) and this oldness and crowding and impracticalness, so I was sort of chocked by these external factors...but you get used to it, of course you get used to it..."

The interviews were made in different rooms each time, usually when the children were sleeping so that the mother could concentrate on the interview. The staff was quite neutral to the whole study at the beginning, but they became more and more interested. They tried to facilitate the research work, for example, by helping with the contacts with the mothers and by offering their rooms when it was difficult to find a quiet place to hold the interview.

The interviews were taperecorded and fully transcribed, except for parts that had nothing to do with the subject, for example when the mothers wanted to talk about something else in the middle or after the actual interview. This happened with two mothers, but these mothers where not excluded from the study because the fact that they did not want to talk (much) about the clefted child cast light on the cleft-problem in a social context. All the tapes were saved to make it possible to return to them whenever needed.

One of the first interviews was not taperecorded, and the mother considered this a good strategy - she felt flattered by the fact that all she said was written down, and she talked in an extremely open way. Despite this advantage, I felt that I could not concentrate on the interview and that it was impossible to write down everything that the mother said in her own manner. Thus, the rest of the interviews were taperecorded. When transcribed, the interviews were about 1000 pages.

2.5 Summary

The emphasis of this study is on the unique interpretation of our experiences, which is the central focus of phenomenological psychology. The method used is in harmony with this approach: the phenomenological method that goes back to the things themselves. This is done in four different steps: By bracketing our preassumptions, by describing, not explaining, by horisontalizing all phenomena and by seeking out the structural or invariant features of the phenomena (structural synthesis). However, the study will also probe the existential aspects of clefting.

In order to gain access to the experiences of mothers of infants with cleft lips and/or palates, 40 mothers of one-year-old infants were interviewed. The interviews started in March 1991 and the study was completed in September 1992.

The interviews were taperecorded (except for one) and transcribed. The following chapters offer access to the experiences of these mothers.

PART TWO: EPOCHÉ

1. BRACKETING

The first step in a phenomenological approach is the first part of epoché. This means stepping back from our ordinary way of looking at things, to shift from a "natural attitude" to an attitude of reflective thinking (Ihde 1986, 32). This rule urges us to suspend our expectations and assumptions, to bracket initial biases (Spinelli 1989, 17). Husserl also talk about using the "index of uncoupling", to exclude all "transcendental placings" (Husserl 1989, 45, 80).

How can we do this? And what is a "natural attitude"? A natural attitude can be described by introducing the concept of tacit knowledge (Polanyi 1961; Polanyi 1962, Polanyi 1964). Tacit knowledge is knowledge that stems from direct experience, a pre-theoretical knowledge. This knowledge is an important - and ever-present - factor in daily human judgement. Thus it is important to make oneself explicitly aware of one's tacit knowledge by reflecting on what is already known about a problem. (Salner 1989, 56 - 57.)

In education, "tacit knowing" has been described as a pre-philosophical understanding that is not articulated - teachers, for example, occasionally possessed great pedagogic wisdom before pedagogy became an object of research (Vandenberg 1974, 188).

Since tacit knowledge seems to be a strength, not a weakness, why is it then so important to articulate it and to bracket it?

The basis of human understanding can be said to rest on our tacit knowledge and on empathy (our emotional identification with a mental intention), but this is not enough to validate our interpretations. Our interpretations must be validated by the activity through which we test and criticize our tacit and empathic knowledge (Ricoeur in Salner 1989, 63).

This means that the basic attitude in this first stage is that of Cartesian doubt. But to doubt only one's own tacit knowledge about a problem is not enough. Husserl emphasizes the importance of bracketing the theoretical knowledge: to him objective science is transcendent (but the knowledge we get when we are thinking about how we think is immanent) and has to be bracketed in order to be able to attend to the things themselves. But why? Because the results of science are questionable and may lead us to wrong solutions (Husserl 1989, 45). This is, however, just temporarily: epoché begins with questioning all knowledge, but it does not stop there. The value of earlier research is not questioned per se, it is questioned temporarily in a stage of the research process where a direct appliance could lead to incorrect or hasty solutions.

In this study my empathy for the interviewees was based on my own experiences of becoming a mother of a child with a cleft lip and palate. During the study, I also became aware of the tacit knowledge that I had about the problem, and also of the tacit knowledge of the problem the mothers that I was interviewing had. Since my activity in the cleft palate problem was not limited to doing research on the subject (I was also engaged in the Cleft Palate Association and planning and participating in educational activities addressed to families), I slowly became aware of the tacit knowledge shared by people that had no particular experiences of the problem.

The following list contains theories that should be bracketed before we can go "back to the things themselves", and in addition knowledge that we "already know" about the cleft palate problem - our pre-theoretical, tacit knowledge.

Both tacit and theoretical knowledge about the cleft palate problem can be organized under certain topics. The first topic concerns immediate parental reactions when the baby is born. A number of investigators agree that the child's birth often precipitates a major family crisis (Irvin, Kennel & Klaus 1976, 168; Cullberg 1979). This crisis includes different stages and feelings of mourning and grief, of guilt, sadness and anger. Thus the first topic to be discussed is the family in crisis.

1.1 The Family in Crisis

The concept of crisis is well known from classical esthetics: a crisis is a turning-point, and according to Habermas a crisis can be seen as a process that deprives an individual of a part of his autonomy. This deprivation of a person's autonomy is caused by objective forces, thus the individual might have feelings of having been doomed to passivity or of loosing the control of his own life (Habermas 1984, 157 - 158).

Crisis is represented by the Chinese characters meaning both danger and opportunity. The danger is its threat to overwhelm the person or family involved, whiie the opportunity is the fact that successful mastery often strengthens people's ability to cope in other areas (Irvin, Kennel & Klaus 1976, 175; Clements & Roberts 1983, 145).

According to Cullberg, crises can be divided into two different groups: *developmental crises* and *traumatic* (or situational) *crises*. Parenthood radically alters the parents as people and changes their lives (Lagerberg 1983; Furneaux 1988, 3). This radical change in their life has been described as a developmental crisis (Cullberg 1979, 11; Ijäs 1984). A traumatic or situational crisis is an unanticipated event and thus comparable with the classical concept of crisis described above. When a malformed child is the first-born of a family, these two types of crises are combined.

Since a traumatic crisis includes mourning and grief, a study of the literature describing the stages of grief might enlighten the problems that have to be faced by parents of an infant with a congenial malformation. Major researchers in the area of grief have suggested that grief may be conceived of in terms of a series of stages (Littlewood 1992, 53). Generally, aspects of the grieving process have been described in a context of a major loss within a family, and the stages of grief for parents facing the birth of a malformed child can be different from the stages of grief for parents who have lost their child. However, the analysis of Solnit and Stark (1961) suggests that parents of a malformed infant have to mourn the loss of the dreamed-of or planned-for infant (the healthy one that they were expecting) before they can become fully attached to the living defective infant. The parents, and especially the mother, create an inner representation of the child during pregnancy. (Recent studies indicate according to Stern (1994) that this inner representation grows stronger between the fourth and seventh month of pregnancy, but decreases slightly in strength between the seventh month of pregnancy and birth, apparently in order to reduce the possibility of discrepancy between the dreamed-of infant and the real infant.)

In the mother's mourning reaction to the loss of the image of the expected baby is included feelings of narcissistic injury. This narcissistic injury is often intolerable, because the mother feels painfully defected herself when she is caring for her defected child (Solnit & Stark 1961, 528).

Irvin et al. (1976) have identified five stages of emotional reactions among mothers of babies with different congenital malformations (Irvin, Kennel & Klaus 1976, 171-174):

First stage: Shock

The initial response of most parents to the news of their child's anomaly was an overwhelming shock. This early period was characterized by crying, feelings of helplessness, and sometimes an urge to flee.

Second stage: Disbelief (denial)

Each parent in this study reported that he or she wished either to be free from the situation or to deny its impact.

Third stage: Sadness, anger, and anxiety

The most common emotional reaction was sadness, but a smaller number of parents reported angry feelings. The anger can be turned against hospital staff, relatives, oneself, or the baby. Most of the mothers were hesitant about becoming attached to their babies.

Fourth stage: Equilibrium

Parents reported that they adapted to the situation gradually. Some parents reached equilibrium (balance) within a few weeks after the birth, but even at its best this adaptation continues to be incomplete.

Fifth stage: Reorganization

During this period parents deal with responsibility for their children's problems. Many couples relied heavily on one another during the early period, but in some instances the crisis of birth separated the parents.

This description of the stages of emotional reactions is consistent with other descriptions, see for example Cullberg (1979) or Furneaux (1988). In Cullberg's and Furneaux's descriptions the first two stages are not separated, thus connecting the stage of shock with the stage of disbelief. However, I do not consider this difference a major one.

Another claim about the process of mourning is that mourning cannot be as effective when the damaged child survives (Solnit & Stark 1961, 533). D'Arcy (1968) observed that the mothers' sense of loss and grief (when the child died) was more acute than that of mothers of surviving infants with severe malformations, but the mothers in the first group recovered sooner than the mothers in the second group. This result must be interpreted with caution, and it must depend on the severity of the malformation.

Two claims can be extracted from this theoretical background:

1. **It is more difficult for the parents to accept the situation, if the defected child is their first child. (The combination of two crises.)**

   and

2. **Parents of a child with a congenital malformation have to mourn the loss of the dreamed-of infant before they can bond to the living defective infant.** (Solnit & Stark)

These two claims were a part of my own preunderstanding of the problem and must therefore be tested and critisiced.

The next topic to be discussed is the attachment and bonding processes when the child has a congenital malformation.

1.2 Attachment and Bonding.

Attachment

Attachment and bonding are related concepts, both referring to affectional relationships between people. In this context, *attachment* refers to the tie of a child to his mother (or a primary caretaker), while *bonding* refers to the tie of a mother to her child. These concepts are used however interchangeably by many writers (Bretherton et al. 1991, 1-2), and attachment behavior is not confined to children. We also see attachment behavior in adults whenever they are anxious or under stress. (Perry 1983, 110; Bowlby 1988, 3-4; .)

The attachment theory was first described by John Bowlby, who calls his approach an ethological approach (Bowlby 1988, 3). In his theory, attachment consists of an inner representation and cannot be observed directly. Its presence is inferred from behavior, such as crying, sucking, smiling, clinging, and following. This is a partially pre-programmed set of behavior patterns that have the effect of keeping the child in more or less close proximity with his mother figure. A child's attachment behavior is activated especially by pain, fatigue, and anything frightening. The biological function of this behavior is postulated to be protection. (Bowlby 1988, 3.)

For attachment to occur, the primary caretaker (usually the mother) must be accessible and responsive to proximity-seeking behaviors and must provide a large proportion of the infant's care over a period of time. Bowlby states that every new-born baby has an innate tendency to remain close to his primary caretaker and that adults, especially mothers, have an innate tendency to remain close to the child and protect it (Bowlby 1988, 120 - 123).

Attachment theory has offered insight into the relationship in the mother-child dyad. But the theory has certain limitations: it does not offer an insight into the dynamics of the relationships between children and parents in a more complex family setting (Singer 1992, 130). The "monotropy hypothesis" that a child attaches itself only to one mother-figure has not been confirmed: research shows that children can be equally attached to both their fathers and their mothers. (Van Ijzendoorn et al. in Singer 1992, 130.)

Infants, however, do differ in their attachment behavior. Ainsworth has studied infants in Strange Situation Assessment which offers an opportunity to observe how the infant responds, first in his parent's presence, next when he is left alone and later when his parent returns (Bowlby 1988, 10). She has classified infants as presenting either a secure attachment to the mother or one of two forms of insecure attachment to her. The pattern of attachment a child develops to his mother is the product of how his mother has treated him: a child whose mother is sensitive, accesible, and responsive develops a secure attachment to her. Consequently, a child whose mother is insensitive or rejective develops an insecure attachment to her.

The primary factor in attachment has been thought to be feeding. But feeding and hunger are only one element in the development of attachment. This has been demonstrated in the well-known experiments of Harlow, who separated infant monkeys from their mothers and raised them with artificial surrogate mothers. In these experiments, the infant monkeys preferred the soft, padded "mother" and did not become attached to a "mother" made of wire mesh, even if they got their food from the wire mother (Maccoby 1980, 63).

Thus, in the ethological approach, attachment is a fundamental form of behavior with its own internal motivation, distinct from feeding and sex (the two sources of human motivation that, according to Bowlby, for long widely regarded as the most fundamental) but of no less importance for survival.

What do Harlow's experiments with the monkeys actually prove? They prove that feeding is neither a necessary nor sufficient condition for attachment behavior among monkeys, they also prove that monkeys prefer a soft mother (the comfort of contact) to a wire mother. (On the other hand, monkeys that are separated from their mothers become emotionally disturbed and are incapable of taking care of their own offspring (Hansen 1992, 26-27)). But do these experiments really prove that feeding is not a primary factor for attachment among new-born infants?

In a psychoanalytical framework, attachment is explained in a somewhat different way. Attachment is an instinctal drive and the mother is the object of the drive: the child does not and should not become attached to anyone else than his mother. Once attachment to the mother is assured, other attachments may begin. (Perry 1983, 110.)

Within this framework, the first stage following birth is called the oral stage, because an infant's primary source of pleasure comes from stimulations of the oral part of the body: the infant has a tendency to suck his thumb and to put any object which he gets in his hand into his mouth. According to Freud's theory, this pleasure in oral activities develops through the connection between nursing and being fed (Baldwin 1967, 354.) According to Erikson, the quality of parental nurturance that a child receives influences the quality of the basic trust he develops (Lidz 1970, 27; Erikson, 1965, 239-242; Erikson, 1985, 32.)

Winnicott, who went to great efforts to make psychoanalytical theories of child development accessible to "ordinary people" (Dahlin 1983, 7), especially for mothers, calls the feeding of an infant a relationship between the child and his mother, the love-relation in practice (Winnicott 1983a, 34). Bettelheim and Klein, just to name a few theorists, have also pointed out the connection between the first relation (to the mother) and the first experience (to be fed) (Bettelheim 1989, 278; Phillips A. 1991, 67).

Selma Fraiberg has reported the link between failure to thrive among infants (without any organic reasons) and maternal deprivation (Fraiberg 1990). She points out the importance of who feeds the infant and the importance of the proximity to the mother (both in a physical and an emotional sense). (Cherniss, Pawl & Fraiberg 1990, 123.)

There is also strong evidence that the interaction between an infant and his primary caretaker in feeding situations has an impact on the feelings connected with food and eating later in life, and that eating disorders (among older children and teenagers) may be rooted in early feeding experiences (Bruch 1970, 307).

In an ethological context, feeding is not seen as a necessary (or sufficient) condition for attachment. This could lead to the conclusion that disturbances in feeding patterns have no effect on attachment behavior. In this study, the conclusion however is the opposite, and this opposite conclusion is also based on ethologically-oriented research: Ainsworth and her colleagues have studied feeding patterns as a part of the mother-infant interaction to see whether patterns prevailing during the first year will predict the strength or weakness of attachment to the mother at the age of one year (Maccoby 1980, 85-87).

They found that prediction was possible: by studying twenty-six infants and their mothers they identified nine feeding patterns, which could be arranged along a continuum reflecting the degree of maternal responsiveness to the infant's signals and states. Then they observed twenty-three (of originally twenty-six) infants in the Strange Situation and found that every one of the one-year-old children, whose mother's feeding patterns reflected relatively high sensitivity patterns, showed secure attachment. Among the rest, that is among the infants whose mothers showed relatively insensitive feeding patterns, ten showed either avoidant or resistant insecure attachment, and only two showed secure attachment. (Maccoby 1980, 87.)

It seems evident that, despite which view of attachment one prefers, there is a strong link between feeding and attachment, and especially when feeding is seen as an interaction between the mother and the child. To be fed by just anyone is not enough; in fact an emotionally-deprived child can die, despite the fact that he is physically well-treated and fed. Elkind & Weiner also suggest that intensive one-to-one care is not necessary in order for infants to become attached to people: "attachment is formed not to those who spend the most time... but to those who are most stimulating and responsive" (Elkind & Weiner 1978, 123).

For an infant with a cleft palate, these early feeding experiences may be somewhat different than for a normal child. If feeding and eating processes are connected with early attachment processes, as is suggested in this study, children with cleft palate are in a risk category for disturbances in the early attachment process.

From attachment theories one can extract two more claims to be studied:

3. **Eating and feeding difficulties may disturb the early attachment process.**
4. **A disturbance in the early attachment process might lead to low weight-gain.**

Especially the last claim has to be studied with a great deal of caution, since a low weight-gain among children with a cleft palate may also be explained by organic and genetic reasons.

Bonding

In this context, *bonding* is the unidirectional process of a parent (mother) attaching to an infant. Bonding is a rapid process that occurs, or should occur, soon after birth - in fact, bonding can be a process that begins during pregnancy (Perry 1983, 308; Bretherton et al. 1991, 1). This process is seen as natural: a woman becomes a mother simply because she gets a child, and if they both (the mother and the child) are healthy and the mother gets enough support from her environment (from her husband and from official supporting systems) the bonding between the mother and the child develops naturally (Winnicott 1983a). She becomes a "good-enough mother", and adapts herself perfectly to the needs of her child, sometimes by neglecting the needs of the rest of the family (or of herself). (Spitz 1965, 95; Lebovici 1970, 5; Davis & Wallbridge 1984, 47.)

Even in this optimal situation, bonding can be facilitated or delayed by infant care practices Klaus and associates suggest that there is a sensitive period in humans when bonding occurs. In their study, one group of mothers was provided with early and extended contact with their infants during the first 3 days after birth. A control group had contact according to the hospital routine. Differences in maternal behaviors were observed at one month and also at one year after birth: the mothers with extended contact were more likely to sooth their infants, they showed more physical affection during feedings and had more eye-contact. (Klaus & Kennel 1976; Maccoby 1980, 50; Perry 1983, 115.)

In this study, the situation is not optimal. The child is not normal: the appearence of a child with a cleft lip with or without a cleft palate can be terrifying to his mother. If he has a cleft palate, he usually cannot be breast-fed. What do bonding theories say about children with abnormal appearence and eating difficulties?

Stern suggests, inpired by Lorenz, that a new-born baby has a biological figure or shape (big eyes, round and soft cheecks, a round forehead and so forth). If this figure is not normal enough, the mother's mothering behavior is hindered or disturbed (Stern 1982, 43). According to this ethologically-inspired theory, the process of bonding can be disturbed if the child has an abnormal appearance.

There also seems to be a connection between hormonal processes and bonding. The stimulation of the mother's nipples by the infant's sucking releases a maternal hormone called prolactin, which facilitates the production of milk. This same hormone is also believed to make mothers more sensitive to the signals of their babies. Another maternal hormone, oxitocyn, is known to facilitate maternal behavior among animals and believed to facilitate maternal-infant bonding. Thus, a system of reciprocal reflexes (sucking - hormonal release) is quickly transformed into an integrated system of mutual behavior. (Maccoby 1980, 47; Hansen 1992, 15, 17-18.)

When shifting the perspective from an ethological to a psychodynamic one, the problem with a new-born child with a cleft might be interpreted in a somewhat different way. We know now that new-born infants are capable of seeing very well at a distance of about 20-25 cm. This distance is the same as the distance between the infant and his mother when he is breast-fed. This eye contact is of great importance, not only for the mother, but also for the child (Davis & Wallbridge 1984, 129). In normal (or optimal) situations, the mother is reflecting the child, as a mirror. Thus, when the child looks into his mother's eyes, he sees the reflection of himself. This reflection is of great importance for the developing self-concept of the child. But if the mother is worried, or occupied by other thoughts, the child does not see the reflection of himself. Instead, he sees the face of his mother. If the mother's expression is that of disgust, this feeling might become an integrated part of the self of the infant. (Piaget & Inhelder 1969, Rosén-Sandahl 1983, 40; Winnicott 1983b; Bettelheim 1989, 24; Igra 1987, 152, Schaller 1992, 49.)

Femininity is often connected with the capability to give birth to healthy children. Therefore, when a defected child is born, this is often felt as the mother's personal failure. This can lead to strong crisis reactions, including feelings of guilt and mourning. If the mother's self-concept is negative, the defected child might be seen as a confirmation of the negative self-concept. In consequence, it can be difficult for the mother to develop a warm bonding to the child. (Cullberg 1979, 114 - 115.)

More evidence of problems connected with a physically-different child with or without eating difficulties can be found in studies on child abuse and neglect.

Child Abuse and Neglect.

Having an infant with a congenital defect is undoubtedly very stressful for parents. Feelings of wishing to reject the child have been reported (Furneaux 1988, 15), and it has been suggested that some degree of rejection is always present.

Several studies on child abuse and neglect confirm that premature or low birth-weight babies, handicapped and temperamentally-difficult children are at risk of abuse. (Crittenden & Ainsworth 1990, 432; Zigler & Hall 1990, 50.)

Children with clefts and/or feeding difficulties are also identified as children at risk, in a study by Ruth and Henry Kempe (1981). Sometimes the cleft is also associated with low birth-weigth and with separation immediately after birth.

It is also suggested that according to the extent to which there is parent-infant bonding, the likelihood that abusive behavior is directed towards the infant would be reduced. In a British study (Parke & Lewis 1981, 186 as reported by Lynch 1976) it was found that 40% of the abused infants were separated from their mothers at birth.

Physically-different children suffer more than their share of child abuse. This might be a paradoxical effect of the suppression of the former patterns of managing deviance in Western societies: as mentioned in the introduction to this study, there has been a transition from "infanticide tolerant-societies" to "infanticide intolerant-societies". Scheper-Hughes (1990) also suggests another transition to "child abuse tolerant" societies. She argues:

> "The difference between allowing certain neonates to die for ecologic or 'ethnoeugenic' reasons in a traditional society and the hostile battering of a stigmatized child in a modern industrialized society needs to be explored. The two patterns are not only distinct, they are nearly mutually exclusive. They represent the difference between cultural norm and cultural pathology, between human exigency and malicious intent" (Scheper-Hughes 1990, 301).

This can be interpreted in many ways. In a modern society primitive impulses (such as infanticide), no longer socially acceptable, might be transformed into other forms of behavior (such as child abuse). They can also be transformed into child neglect or into only minor disturbances in bonding processes. However, the early bonding process can be facilitated by providing early information for parents and by avoiding other stress factors such as separation.

According to bonding theories, two more claims can be added to the list:

5. **Early maternal-infant bonding might be disturbed if the child has a visible malformation.**
6. **Early maternal-infant bonding might be disturbed if breastfeeding is impossible.**

So far it seems that feeding difficulties might lead to problems in both attachment and bonding processes, while a visible malformation would lead to difficulties only in bonding processes. It also seems that a disturbance in the early bonding process might have serious consequences, such as child abuse or neglect.

Claim number 6 is a conclusion drawn from the theory of the connection between hormonal processes and bonding, thus a compromise of extracting milk with a breast pump might facilitate the bonding process. One might suggest that while breast feeding might have an important impact on both attachment and bonding processes, extracting milk with a breast pump might only have an impact on bonding processes. These conclusions also have to be criticized and tested, because there is no research available that would confirm these conclusions.

There were also some indications that early separations might disturb the bonding process. Thus the next topic to discuss is separation and maternal deprivation.

1.3 Separation and Maternal Deprivation

A human child rarely experiences full-scale maternal deprivation, without the opportunity to form attachment to anyone. Partial maternal deprivation, for example prolonged or repeated disruption of the mother-child bond during the first five years of life, is however considered hazardous. Such separations are known to be especially frequent in patients later diagnosed as psychopathic or sociopathic personalities (Bowlby & Parkes 1970, 197).

Erikson strongly believes that the sense of trust that mothers create in their children forms the basis of the child's sense of identity. At this point, researchers seem to reach consensus: thus theoreticians like Erikson (1965), Spitz (1965), Winnicott (1983a and b), Bowlby (1988), and Mahler (Mahler, Pine & Bergman 1984) all warn against prolonged separations during the first five years.

These disruptions leave the child emotionally insecure, and will show their effects later in life. After a separation, children are likely to appear detached, they may cry, turn and walk away and even seem not to recognize their parents (Elkind & Weiner 1978, 125). In the well-know study of Spitz, the children that were deprived of their mothers got into a state of anaclitic depression (partial emotional deprivation), and if the separation was prolonged the emotional deprivation became total (hospitalism). Some of the children became completely passive with death as a result (despite the fact that they were physically well treated) (Spitz 1965; Spitz 1975).

There are several other studies that confirm the results of Spitz and Bowlby (Feldman 1980, 149; Jeffmar 1983, 79, 83; Hwang 1992, 114;). Of special interest has been the situation of the child in hospital. It has been suggested that it is not enough for a child that his mother visits him once a day - this will not eliminate the negative effects of separation. The optimal situation for the child is that one of his parents can live with him at the hospital - this has been reported to facilitate the child's recovery after a surgery (Feldman 1980, 155)

In Finland it has not been possible, so far, for a parent to stay at the Cleft Palate Center at night. During the day the parent (or both of the parents) may stay at the hospital from early morning until late in the evening, without any restrictions. Most of the parents have used this opportunity, but not all of them. In this study, some of those mothers who did not stay with their children at the hospital were interviewed.

The last claim, extracted from theoretical issues is the following:

7. Separation from parents might have negative effects:

- **emotional insecurity (attachment)**
- **child abuse or neglect (bonding)**

What remains unclear is to what extent a child can recover from the negative effects of separation, and researchers have not reached consensus on this point. More recent work, following that of Bowlby, has indicated that children may recover from separation quite fully, if their circumstances are adequate (see for example Maccoby, 1980, 98, as reported by Yarrow and Goodwin 1973). Another aspect of this is how mothers and fathers react to separation from their children; but as stated above, separation might have negative effects on both attachment processes (emotional insecurity) and bonding processes (child abuse or neglect).

1.4 Summary

The claims extracted from the theories were the following:

1. **It is more difficult for the parents to accept the situation, if the defected child is their first child.**
2. **Parents of a child with a congenital malformation have to mourn the loss of the dreamed-of infant before they can bond to the living defective infant.**
3. **Eating and feeding difficulties may disturb the early attachment process.**
4. **A disturbance in the early attachment process might lead to low weight-gain.**
5. **Early maternal-infant bonding might be disturbed if the child has a visible malformation.**
6. **Early maternal-infant bonding might be disturbed if breastfeeding is impossible.**
7. **Separation from parents might have negative effects :**
    - **emotional insecurity (attachment)**
    - **child abuse and neglect (bonding)**

Those seven claims might be seen as premisses. It is possible to draw three conclusions from these premisses:

First: The cleft lip and palate problem (CLP) is the most severe:

- eating/feeding difficulties (attachment+ bonding)
- visible defect (bonding)

Second: The cleft palate only problem (CPO) is the second most severe:

- eating /feeding difficulties (attachment + bonding)

Third: The cleft lip-problem (CL) is the least severe of the diffrerent cleft types:

- visible defect (bonding)

This can be illustrated by the following table:

	Cleft type		
Claims	CLP	CPO	CL
3	x	x	
4	x	x	
5	x		x
6	x	x	
Total	**4**	**3**	**1**

Table 5. Cleft type and degree of severity.

As we can see from the above table, the clp-children get 4 points for the degree of severity, the cpo-children get 3 points and the cl-children only 1.The conclusion drawn from attachment and bonding theories is that a cleft lip must be classified as a minor problem as compared with cleft palate and cleft lip and palate.

However, tacit knowledge about congenital malformations seems to be that if a malformation is visible, it is more difficult to adapt to than if it is not; and this tacit knowledge was a part of my own pre-understanding.

In this study, the focus is on the maternal - infant bonding process. The study of attachment processes would require a different type of study, for example a study on the attachment behavior of children with a cleft (for descriptions of different studies on attachment behavior, see Ainsworth 1990 and Greenberg, Cicchetti & Cummings 1990). As has been shown, all types of clefts might disturb the early bonding process. The conclusion, drawn from both attachment and bonding theories that cleft lip must be considered a minor problem as compared with cleft palate and cleft lip and palate, must therefore be examined in this light. Since both visual and functional problems might disturb the bonding process, it is not possible to state at this stage which problem must be considered as more severe from an early bonding point-of-view (naturally bonding and attachment processes cannot be separated from each other from a broader perspective, since they reflect one another).

In this study, only claims 1, 5 and 6 can be studied. Number 2 is a claim that can neither be verfied or falsified, but it can be examined by its explanatory relevance. Number 4 will be examined by referring to previous studies of the weight-gain of children with a cleft. Numbers 3 and 7 would require a different type of study (attachment behavior of children with cleft palate). This study, however, will include the mothers' experiences of separation from their children.

It is important to note that this study will not be restricted to examining the claims. By these claims, the theories have been brought to a thematic level, and in the next part of the study these claims will be set aside, bracketed.

2. DESCRIPTION: THE LIFE-WORLDS OF THE MOTHERS

The second rule of the phenomenological method is the *rule of description*. Explanation is excluded in this initial phase, because early explanations may lead to misinterpretations. By explanations we try to go behind phenomena, to seek reasons, and this may be an obstacle to attending to phenomena as they appear (Ihde 1986; Spinelli 1989). There is also another aspect of this rule: to seek reasons might lead us to seek simple causality connections between phenomena where such connections are non-existent. Thus an early search for reasons and explanations will offer us a simplified model of the phenomenon under study.

We have to be able to bear ambiguity and to handle a somewhat chaotic reality in order to be able to follow the rule of description. This is also one weakness connected with this method, because it seems to require the impossible of the researcher. But even if the researcher is able to overcome the difficulties of handling a chaotic reality, and to overcome the temptation to seek early explanations, other problems will remain. In this study many of the mothers offered explanations for their feelings and behavior even if they were not asked to offer any. Such explanations were considered to be descriptions of explanations, not explanations per se.

By trying to avoid early explanations the researcher avoids the temptation to appeal to single elements for explanation, in other words to do "exampling" - a researcher will always be able to find an example that proves the explanations he prefers (Silverman 1989, 28, Glaser & Strauss 1967.)

In this chapter I will offer the reader a possibility to enter into the life-worlds of the mothers that I interviewed. No attempt is made to find typical cases, the attempt here being to describe the richness of the cases, to describe individuals who differ from each other, and to describe some of the topics (I prefer not to use the word "categories" in this context) that the mothers wanted to talk about. In this phase, it is enough that one mother has talked about a topic for it to be included in the description. Later in this study topics that were more typical will be returned to in order to find invariant features of the phenomena under study.

2.1 Description of some cases: Mothers Talking.

As I mentioned above, I will here present to you some of the information-rich cases that differed from each other. But these cases are not typical, just subjective experiences as they were told by the mothers in an interview situation. However, the cases were chosen so that they represented three different types of cleft: cleft palate (case number 1), cleft lip (case number 2) and cleft lip and palate (case number 3). They were also chosen because they did not confirm my pre-assumptions of the cleft palate problem (that the visual problem is the most difficult to adjust to). Also, these mothers differed from each other in their interpretations of the cleft palate problem, and in their own way show the variation of the interpretation possibilities in the whole of its extent.

The names and some other facts are made up and the appearance of the mothers will not be described (even if I took notes on these things) for the delicate nature of these interviews. Thus the rule of "thick description" is not followed for ethical reasons.

The interviews are transcribed in the following way:
... means that the mother hesitates, or takes a pause in her talking
/ means that some sentences are left out in-between
--- refers to the name of the child
( ) a word in parenthesis is added to the sentence to make it more intelligible.

Case number one: "Somehow I feel that I've always done everything wrong"

This mother had a girl with a cleft palate only, with no other additional problems. The little girl was one year old at the time of the interview. The interview took place at the Cleft Palate Center. The cleft had been closed some days earlier and the surgery had been successful. First I felt that she was not very eager to take part in this study, but when the interview began she was extremely open and did not avoid talking about difficult topics. I also had the feeling that the situation was in a way therapeutic for her: sometimes she talked almost to herself, and the transcribed interview is perhaps somewhat difficult to understand. However, no particular attempts have been made to make the quotations more intelligible.

The child was the first child of the family. The mother had a white-collar background and the father an academic background. And here is her story (I = the interviewer, M = the mother):

The girl was born at the due time in a big central hospital. The father was with the mother at the time of the birth. The mother was disappointed because she felt that she was not able to give birth to her child without extra help (the delivery was facilitated by a suction cup), and because she felt that she had not been given the possibility of holding her daughter long enough immediately after the birth:

M: "But I had the impression that she was only there for a moment and then snatched away and brought back all wrapped up...I think that if she had been there naked beside me and I could have looked at her, there would immediately have been a feeling of closeness, there seemed to be a time that she was quite strange to me. Afterwards I was annoyed that I didn't get to know her at the maternity hospital. They always say that it is very important from the child's development aspect. Somehow I feel that I have always done everything wrong, first I couldn't give birth properly, then I could not feel towards the child properly."

I: "Have you somehow a feeling that you missed something?"

M: "Yes I too missed something, although --- missed something as well. I don't know why I couldn't take her, it was certainly to do with her head being flattened (produced with suction cup on back of head), I had never seen a new-born baby...and it was terrible looking (laughter), I thought she was ugly and I felt terrible seeing her, and had a feeling that I didn't want to touch. And all in all, for a long time afterwards I have though that I quite consciously left her so that I didn't even touch ---, always when I took care of her I looked in the other direction, because she was so awful. The doctor once suspected that with the head being that shape there could be other faults, and that's how the whole thing began about me starting to suspect that something was wrong in her head or that she was retarded. Always when someone said that she was so cute and everything, I just thought that they were teasing, because she was so terribly ugly, that they were having me on."

At the hospital the girl was checked thoroughly and she was confirmed to be healthy with a small cleft in the soft palate. But the mother did not believe this:

I: "Was it a relief to you, did you believe that?"

M: "In a way, but I didn't believe (laughter) but in a way it was a relief...but for a long time I was watching her and how she behaved...and then I feared that something was wrong in her heart and I feared up to this moment when I thought that her heart could not stand an operation, and I was surprised when there was no cardiogram taken."

She had imagined the time after the child's birth as a rosy time, and she felt that all the mothers she knew were happier than ever when they had got their first child and that she was the only exception to this rule. The father took several weeks' vacation after the child's birth, and during this time the mother pretended to be in such bad shape after the delivery that she had to stay in bed. And she let her husband take care of the girl. But then the father went back to work and she was left alone with her baby:

M: "Then my husband left back for work and then I had to be with --- and then gradually I had to touch her and change her nappies, wash her, and obviously this is where I began to gradually get to know her.Now afterwards I think that I have been rather dumb, but at that moment I couldn't help it. When I made the first eye contact with --- then that was when I began to think that her forehead would straighten out, and then certainly the smile, when she once smiled I felt like crying...then it felt like we would manage even with the defects and everything."

I: "Do you now have a more confident feeling when no doctor has found anything wrong with her?"

M: "Yes I have and now I have the feeling that there is nothing wrong with her (laughter) and believe that...at some stage I dared to say (to my husband) that I wondered if she was quite normal and he said that if someone strongly believes in something then someone can produce an illness and then I stopped, I thought that if I start to think that she is very developed and ahead of the rest, then that's the way it will be."

I: "Did it help when you started to think that she was ahead of the rest?"

M: "It did help when I compared her with my friend's daughter, who was fatter, while --- got over her fatness at birth and has been afterwards quite skinny and my friend's daughter the whole time has been a small and chubby kid like they should be...and the neighbor's boy who is far worse in motor aspects. Now I have noticed that children develop in different ways and you can't compare them, some can develop fantastically in a month, should I go to some psychiatrist or somewhere where there are small children as I haven't seen how they are, as I haven't dared to look at little kids? Really all in all her cleft was just a side issue compared with all the rest."

I: "Do you think that because of the cleft you began to have doubts about everything else although the cleft itself was not a bad thing?"

M: "Yes, because the doctor said so and when the doctor begins to suspect that there is something else ... and through that I began to suspect everything already at the hospital".

I: "Have you ever had any literature on children with cleft palates?"

M: "I did get some from the maternity hospital, and I didn't dare read it...it had a lot of things about those, who have a cleft all the way from the lip and I wasn't able to read it, though my husband read all those things. I now understand him because it is indeed difficult to explain to a person when they can't handle the information and he explained and explained that she is quite a normal child and quite a pretty child...and when I look at the pictures afterwards, yes she was quite a sweet baby and I don't even remember how sweet...so now with hindsight you can say that I had a pretty baby but I didn't see it."

"In the beginning I hated her and then I somehow or other or I don't know if I really hated her but somehow I avoided her and then there was a stage when just like a routine, I let everything just go, well the smile was as --- smiled early, oh why am I such a terribly difficult person. But somehow it seemed that it was a terribly long time before --- got real proper love, it was sort of artificial...but perhaps she has got more love from my husband and mother's love is not necessary, or at least I hope not. Yes, my husband has always given love and I thought, my God, how can he love a child like that (laughter)..."

I: "So you wondered how he could love the child?"

M: "Yes, how in heaven"

I: "You felt that your husband saw her in a different way from you?"

M: "We saw the whole child differently. I didn't see any good sides, and I don't understand why I didn't see...I said already at the maternity hospital that I don't dare become attached to her and my husband said that just stop that, anyone can see how you like her and I thought that how can something show that you don't feel".

I: "So he was not able to accept that it was real what you said?"

M: "No, and at that moment I felt I was quite alone."

She felt that she was alone and she also felt that she was not able to bond to her child, partly because she was afraid that she might lose her. She also found talking about her daughter's cleft to her relatives and friends quite problematic, and in consequence she was afraid that somebody would notice the cleft:

M: "Always when we went somewhere she cried and cried and I thought, that everyone must notice it. Then we bought a big pacifier and I always shoved it in her mouth when she cried...she was certainly 5 months old before we told anyone that she had a cleft palate. Only three people know about it unless they have told others. I know that my mother hasn't told anyone but I don't known about the others."

I: "You don't consider telling people to be important?"

M: "No, I thought that people will get full of pity and then --- will get attention just because she has a cleft, that she won't get it (attention) because of herself. "

I: "In other words even your sister doesn't know?"

M: "No. It always seems that I should have said something or that you should say something to your own sister, but otherwise I wouldn't like to tell anyone. Now it seems that it is such an old issue that you can't talk about it (laughter)."

Feeding the baby was problematic for the mother. At the hospital the nurses tried to help her to breast-feed the baby, but breast-feeding did not succeed. The mother did not get any information on how to feed her baby, and the baby lost weight.

I: "How did you feel about feeding at the beginning?"

M: "I feel that I didn't really put a lot into feeding because of the baby's disability. We were filmed on video quite a lot, which I didn't like at all - being videoed, but afterwards I have watched the tapes and in nearly every one --- is crying and I have thought that hasn't she had any milk at all? Really, when I have thought later that the child cried and cried, I wonder what was in my head when I didn't realize to give more food...but I guess I was satisfied when she got as much as it said in the clinic's instructions and I thought it's enough, if you are stupid you are stupid."

I: "Were they concerned at the clinic about her weight curve not rising?"

M: "Yes. In fact her weight is still being monitored."

No doubt this mother had a difficult time in adapting to her baby. But at the time of the interview the situation was already much better. Now she felt that she loved her little daughter, but she had strong feelings of guilt for not having been a good enough mother for her. She said that at the time she started to think about her baby as a human being and as her own child, she also started to think about the cleft:

M: "When I started to think of --- as a person and my child, and I really liked her and then I started to think that I have caused it and that it is my fault that she has the cleft...then (I thought) sort of that with her having the cleft that she's otherwise good but she has this cleft."

However, all in all she felt that maybe she would now be a better mother for her daughter than she would have been otherwise without her experiences. At the end of the interview she felt that she would use the years to come to build up a relationship with her daughter based on the love that she now felt for her.

Case number two: "Actually it looked as if he were smiling all the time"

This mother was 30 years old and the boy was her first child. Both of the parents had academic professions The couple was married. The boy was born with an incomplete cleft lip. The interview took place at my office at the University. I had contacted the mother by letter and by phone to get the interview. First she said that she would not have much to tell, because she had not had any problems with her son. I told her that I was not looking for extra-problematic cases in particular, and that the very fact that somebody had not had any problems was of equal importance for the study. Then she agreed to participate in the study. We got on well and had a nice time talking about her case.

She had a flu during the first weeks of pregnancy and she read in a newspaper that a flu might cause a cleft. She remembered this immediately when the child was born:

M: "I remembered it immediately and it came to me that I thought it was something that caused it, but certainly no one would admit...that a bout of flu could have caused it."

I: "Did this thing bother you throughout the entire pregnancy?"

M. "No, I must say that I have an optimistic outlook which can leave all unpleasant things in the background, so that I don't let such things affect me."

The father had supported the mother through the delivery, which she felt had been very important

M: "I remember most vividly when the child was put at my breast and it was an unforgettable moment, and then he cried and then when he was put here I remember when my husband said, look how he calmed down immediately, and that it was great."

I: "Was it already clear at that stage that he had..."

M: "It was funny, in fact another midwife came into the delivery room and there they stated the child to be healthy and then they looked again and said there was a small cleft in the lip, that this was you know oh horrible, but then the word "small" was a comfort to me...and in a way we believed that this was not a proper cleft lip, but all in all, it is and here at the hospital they said that this is just one form of it. It was really a terribly neat pleat, just a little pleat as of course when a child is small everything is small... In fact only with growing did it begin to increase in size. Afterwards we have looked at the time when he was 6 months old then it was already rather big, but it was neat looking and really it appeared that the boy was smiling all the time."

The family made a visit to the Cleft Palate Center when the child was six weeks old, and the surgery was scheduled to happen when the child was six months. This first visit made it clear for the parents that their son really had a cleft lip.

M: "In a way it was a disappointment when nothing happened there except that somebody said he has a cleft lip when we thought that this perhaps wasn't a proper cleft lip even, and the doctor put us right and said that yes this is one form and in that way it was perhaps a disappointment."

The mother stayed at the hospital with her child, and she felt that it was an exhausting week:

M: "But the hardest day was that after the operation...yes indeed, it was quite a shock somehow when his face was swollen and somehow when I saw that he reacted immediately when I came in and then it sort of happened that I cried terribly (tears well up in her eyes) but on the other hand everything went then...but however, those people, their routines there were supportive when they said that this is quite normal (she is crying),...I am very emotional...but let's say that it was the most difficult moment of all.

For her it was a surprise that they had to stay for six days at the hospital. She thought it to be a minor operation and she was not aware of the fact that the scar would reach from the lip to the nose. Before the surgery the surgeon explained to her what he was going to do.

I: "Had you thought before this explanation that they would just somehow sew it up?"

M: "Yes I had, that they would just close it. It was a surprise that suddenly they pull it open up to the nose and then the nose repair too. Neither had I understood that there would be something different in the nostril."

I: "Was it a kind of disappointment or were you afraid the scar would stretch all the way up?"

M: "No, not really then. I don't know, it may be that when to me it's a boy in question, I don't know if it were a girl whether appearance would be still a more sensitive thing...and I have gone along with the idea that OK, correct it even if it costs money well enough that the result is neat."

She had not got any information from the hospital on how to feed her baby, but she decided to try to breast-feed him, and this succeeded despite some problems at the beginning. All in all, she breast-fed her baby for six months, and stopped breast-feeding him because of the surgery.

This mother felt that her self-respect had grown, she was proud of her son and felt more secure than before. At the time of the interview she had returned to work and seemed to be satisfied with her life, although she told me that she was surprised at how much her life had changed when she became a mother.

Case number three: "The paediatrician said congratulations parents, you have a healthy baby"

This interview was made at the Cleft Palate Center. The mother was calm, sad but determined, and she did not cry during the interview. She was 26 years old and the child was her first. The boy had a cleft lip and palate, and had gone through three operations by the time of the interview. The parents were going to get divorced and had separated soon after the birth of their child. She had a feeling that there was something wrong with her baby throughout the pregnancy.

M: "I had a feeling that there is something up with my child...I felt and did say to one midwife that what's up with our boy (I thought that it is a boy just like it was)...I spoke with my husband about if the baby is not healthy what then. Always there was talk about if the baby is not well. Then when --- was born the midwife said she would tell us before she showed us the baby that he is not quite well. The father was there at the birth and I feel that he took it hardest...and I wondered what it was with him and then they said it is a cleft lip and palate and this is rather ugly looking, don't be shocked. The midwife was wonderful. It really meant a lot that the midwife was a really nice person, but really I did not feel at all that oh dear, I don't want to see him at all or anything like that, I was quite satisfied...but then over the evening I began to reflect on why this happened to me, why to me and not someone else...and there in the ward when other people had quite perfectly beautiful babies .. and it was a little like that often in the evenings..."

I: "You said that the father took it hard. How did he react?"

M: "He did, and at first when they said that this baby is not well, well he said that Good God...it was a tough moment and he had to go to sit in the rocking-chair and recover a little...he was then already working abroad...but then he just left and although he always called and asked worried how are you managing, but I don't know, he wasn't able to come to the operation and so on. He has been away since then and it has come to the point that we are getting divorced."

I: "Did you feel in the maternity hospital that he somehow didn't want to hold the baby?"

M: "No...he held it and said 'poor thing' and he nursed him and was everyday from morning to evening there at the maternity hospital, but when he left and came home two weeks later, he was then somehow a little shocked and he cried a little that perhaps he wouldn't make a real father."

The hospital helped the mother to get in touch with another mother who had a girl with a cleft palate and these two mothers became close friends. The mother also got information on the cleft palate problem and was quite satisfied.

M: "And in the maternity hospital they said, well first the paediatrician of course said congratulations parents that you have a healthy child and I was quite amazed as he wasn't healthy, but the doctor said that this is a very small defect and can be cured."

She also learned how to feed her baby and she tried to extract breast milk with a breast pump, and succeeded in doing so for two months (which she felt was a failure). The baby's weight gain was good and he was fed with normal nipples.

I: "Had you imagined beforehand you would breast-feed?"

M: "Yes, I was a little disappointed, I had got lots of feeding bras and everything and always saw myself sitting in a rocking chair with the baby at my breast...and then when my sister breast-fed the girl still so...then I began to cry that I myself would have liked to experience it and it was somehow a little wretched."

The mother had thought a lot of what might have been the cause of the cleft:

M: "Yes, I did think what in heaven's name have I done. And then I thought that then at the beginning of the pregnancy we went abroad and went through these safety gadgets and I wondered whether this will affect the baby, and I thought that as I work with a monitor, and things like that."

At the beginning she was impatient to have the lip corrected:

M: "I thought that it should come soon and when there was the christening I thought it would be nice if it was already operated on because there were many people and it seemed he should have got it immediately then, but now again it does not seem so important. But then I was so impatient to see how it would look."

I: "How did you feel after the first operation, he looked a little different, what did that arouse in you?"

M: "I felt, is this the same child, is this the same child, is this the same boy now...and especially after the second operation well, --- was in that room and just being fed when I went to see him...so I actually asked where --- is and he was in her lap and I just didn't recognize...I was so amazed..."

I: "Was it a surprise to you that although you looked forward and wanted the operation a lot, that when it was then done and still you were a little shocked...?"

M: "Yes, it was like that. I just have to get used to the fact that it is now like that and do I dare feed quite normally, but then it all went on as normal."

The mother also felt that she had changed after the birth of her child:

M: "I feel I have changed. Somehow my attitude towards all these sick children...how can I put it...somehow there is this wish that if I could do something I would like to help...Then came a sort of (feeling) or (it seems) quite frankly ridiculous that why should everyone be the same looking. When you look at those magazines, it's just like all people were the same shape. Then if some people have some more individual features or a little fault like this, then it should be covered so much. Yes, I've begun to think a little differently and put life in perspective regarding what is important and what not."

I: "Do you feel that in a way there is something positive in..."

M: "I feel that I have myself developed in some way. Certainly it develops a person...yes, you become a lot stronger after that kind of thing and can take other people into consideration in a different way."

I: "Do you feel that your relationship with your own or your husband's parents has changed?"

M: "Relations have improved with my own parents...I always thought that my mother is someone that doesn't understand anything, but now it's clear that she is an unusually wise person and she has provided a lot of moral support...but my husband's parents have been a little like, well a little hysterical about our divorce thing. They were a bit amazed that how has it come to this and so on. I feel that the relationship with my own parents has changed the most, deepened somehow."

This mother had decided to re-educate herself: she had been admitted to a nursing school.

2.2 Summary

These three cases above are not typical, in the sense that they distinguish between different types of cleft. But they are good examples of stories that made it clear to me that my own initial understanding of the cleft problem would not be enough to validate my interpretations. The subjective interpretation that each mother gave to the cleft problem was striking and did not seem to follow any rules. Interviews like these made me search for a new framework for interpretations, and this I found in phenomenological psychology and the phenomenological method.

Case number one struck me especially because of the following things that the mother said (these are only examples, and will not be interpreted yet):

"somehow I feel that I have always done everything wrong, first I couldn't give birth properly, nor could I feel towards the child properly."

During the interview I felt that the delivery and the child was nothing but a failure for the mother. But was this something that she felt already when the baby was born (or even before?), or was this a feeling that came later because of other circumstances?

"The doctor once suspected that with the head being that shape there could be other faults, and that's how the whole thing began about me starting to suspect that something was wrong in her head or that she was retarded. Always when someone said that she was so cute and everything, I just thought that they were teasing, because she was so terribly ugly, that they were having me on."

Here she offered me an explanation of her problem. The doctor had said that the baby might have additional problems, and because of this she started to be suspicious. However, at this early stage this explanation is seen as a description of her interpretation of the problem. This explanation may be correct or it may not be, but to her it serves a function. (This explanation is also a good example of how difficult it is to study something in a thoroughly descriptive way, as the phenomenological method implies.)

"When I made the first eye contact with --- then that was when I began to think that her forehead would straighten out, and then certainly the smile, when she once smiled I felt like crying...then it felt like we would manage even with defects and everything."

Here she is linking things together, the eye contact with the baby's forehead, and then the first smile to which she returns many times during the interview.

"when I compared her with my friend's daughter, who was fatter, while --- got over her fatness at birth and has been afterwards quite skinny and my friend's daughter the whole time has been a small and chubby kid like they should be..."

She expresses an ambivalent attitude to whether a baby should be "chubby" or not, about her own baby she uses the word "fat" and seems to be satisfied when the baby looses weight - at the same time other babies may be "chubby", because that is the way babies should be. She also thinks that her baby did not get enough food at the beginning, which she is sorry for.

"and when I look at the pictures afterwards, yes she was quite a sweet baby and I don't even remember how sweet...so now afterwards you can say that I had a pretty baby but I didn't see it."

She had a beautiful little girl but she did not see it. She saw her as ugly and malformed (and the head may have been malformed at the beginning because of the delivery) and she could not understand how other people could think that her baby was sweet. And I started to think about what and how we see things - and why. So this mother had a baby with a *visible* malformation even if the cleft was not normally visible. But what was the impact of the cleft in this case?

The second case describes a mother of a child with a visible malformation, which she does not "see":

"they stated the child to be healthy and then they looked again and said there was a small cleft in the lip, that this was you know oh horrible, but then the word "small" was a comfort to me...and in a way we believed that this was not a proper cleft lip. Afterwards we have seen that when he was 6 months old then it was already rather big, but it was neat locking and really it appeared that the boy was smiling all the time."

He had a visible cleft, but the mother did not regard it as a malformation; to her the boy looked as if he were smiling all the time. Afterwards, when she has looked at photos of the baby, she thinks that the cleft was bigger than she remembers - this could be transformed to "he had a cleft, but I did not see it". Again the personal interpretation of a cleft seems to be important

And what can we say about case number three? This cleft was the most severe according to both clinical and psychological classifications. She is also talking about her immediate reactions:

"but really I did not feel at all that oh dear, I don't want to see him at all or anything like that, I was quite satisfied...but then over the evening I began to reflect on why this happened to me, why to me and not someone else...and there in the ward when other people had quite perfectly beautiful babies and it was a little like that often in the evenings..."

On the other hand, the paediatrician congratulated her on having a healthy child and she was given support by the hospital and by another mother in the same situation (I also interviewed the other mother). She seemed to have coped well with the problem, despite the fact that she was not given much support by her husband. She had also created a meaning of this event for herself: she had changed as a person, she wanted to help others in the future.

Three mothers, three different types of cleft, three different ways of coping with the problem. But what did the other 37 mothers talk about?

3. HORIZONTALIZATION: THE TOPICS THAT THE MOTHERS TALKED ABOUT.

The third rule of the phenomenological method is the rule of horizontalization. This rule urges us to avoid placing any initial hierarchies of importance upon the items of our description, in other words to decide too quickly that some things are more fundamental than other things (Ihde 1986; Spinelli 1989). This stage is also a part of the negative reduction, described in the first part of this study.

The first step then is a full transcription of every interview. It is not possible to leave out parts that are not "interesting". After a while two mothers started to talk about another problem, aside from the cleft problem, and they were offered the possibility to do so. But in these two cases, only the parts of the interviews that had something to do with the cleft problem were transcribed. However, all the tapes have been saved and it is possible to transcribe other parts of these interviews as well later.

The next step is to list the topics that the mothers talked about. This might be done by reading the interviews several times (a minimum of four times), to get a "good grasp" (Karlsson 1993, 96) and then extracting topics out of every interview in an inductive way. That means that every interview gets its own topics, not that the researcher lists some important topics and checks if one mother talked about any of these. This also means that the same topic may be labled differently in different interviews at the beginning of the analysis, because the researcher does not even try to get any consistent topics or themes.

This also means that, in order for a topic to be mentioned, it is enough that one mother has talked about it. In Chapter 4 some of the topics will be presented in tables so that the reader may be able to see the frequencies.

3.1 Topics of the Cleft Problem.

When doing this, I ended up with 59 different topics about having a child with a cleft. This is by no means ideal, since it is difficult to handle a chaos of topics.

But when I examined the topics, I found that some of these topics were identical in their contents, but labeled differently. By renaming some topics and by organizing some of them together under certain themes, these 59 topics could be reduced to 18, organized under 7 themes. Here one can argue that organizing the topics already breaks the rule of horizontalization, which is true. But the point is the difference between the *process* and the *presentation*: the process has been that of horizontalization, but when the topics are presented, they are already organized.

Note that this stage is descriptive.

3.1.1 Pregnancy: Presentiments and Guilt

The psychological preparation for a new child normally involves the wish for a healthy child - and the fear of a damaged child. When the child has a physical malformation, this will give a new interpretation to the pregnancy.

In this study, the mothers were eager to talk about their pregnancies, but very soon they focused the discussion upon certain topics. One of the topics that came up when we talked about pregnancy was the *presentiment*, which many of them -but not all - said they had had, that the baby may not be normal in some way. Another topic was the feeling of *guilt*.

Presentiment

The mother of a girl with a bilateral cleft lip and palate, her third child (34):

M: "When I knew I was expecting --- it was spring and a quite peaceful and happy time, and I had not been ill or tired or depressed, quite the contrary. I had had a miscarriage one year earlier, so this pregnancy was quite hoped-for...but this strange, I cannot explain, but a notion, some kind of funny feeling that when --- was born I somehow expected that everything was not all right...of course it is easy to say afterwards. I guess everybody has these fears."

Sometimes these presentiments were more mythical:

The mother of a boy with a bilateral cleft lip and palate, her second child (27):

M: "I felt actually quite good all the time. The only thing that is left, some kind of subconscious awareness that something was wrong and I remember that a couple of months before --- was born I had a terribly strong dream, the dream was in such a way very intense that I thought that the child was dead... I wonder if it was the first subconscious sign that something is wrong..."

One mother (19) told me a story about a dream that her mother had had:

M: "My own mother was the worst (laughs), I mean really. You see, she is the kind that has dreams and she is already old, but anyway, and she said when me and my sister were pregnant at the same time (there is one month difference between our children) so she told me that she had had a dream: that there are two carpets that are alike and two eggs that are alike and a part of one of the carpets was broken and one of the eggs was broken and she said that one of the children is going to be retarded...My sister and I were terribly anxious because we were both expecting babies...my sister had her baby one month before me and I saw that she had a healthy child and I have always thought that when our mother has a dream it has always been right. And so it was this time, when my baby was a little..."

While the previous presentiments can be classified as belonging to normal feelings during pregnancy, the last one is more difficult to interpret. It is not our task to decide whether the story of the dream is "true" or not, but surely the story tells us something about the relationship between the mother in the interview and her mother. And, not surprisingly, the contact with the grandmother was broken immediately after the birth of the defected child.

Guilt

When talking about the pregnancy, many mothers started to talk about the possible causes for the cleft, and about their own feelings of guilt:

M: "First I had a feeling that if it has grown inside me it must be my fault."

M(2):" ...and just kind of why us, us...that why couldn't it all go well and of course I kept thinking that what did I do at certain times.."

M (11): "I haven't really been thinking so much (about the reasons), I have tried to dismiss the thought that --- is a hormone pregnancy which means that I have had a lot of them and it is a pregnancy hormone..so I have had this fright that this might be the reason, but I didn't think about it so much before we went to the maternity care center to see a doctor because --- had been growing so slowly, and then the doctor put it this way that if you have been considering having another baby so you certainly wouldn't even think of having these hormones, and then I thought that my God, it's my own fault..."

Most of the mothers had an explanation to offer, and some of the mothers had strong feelings of guilt.. However, one mother (30) had decided not to blame herself:

M: "..so I decided that what if I didn't blame myself this time (laughs) ...so I didn't think so much about it or worry so much about it."

3.1.2 Immediate and Later Reactions and Concerns

Immediate Reactions

The mother of a girl with a cleft palate only, her fifth child (14):

M: "Thinking about it afterwards everything really went black at that moment...I saw the child as crippled for a few days. I was afraid that she might have, that she might be deaf and I was already imagining that she might never learn to speak...This is what I thought during the days in the (maternity) hospital. I really thought it was a big thing. If only someone had told me that this occurs by itself most of the time."

The mother of a girl with a bilateral cleft, her third child: (34)

M: "I must have had a shock then, I have a very vague picture about it, not so much about the delivery room but moving to the ward, but my husband has told me about it afterwards...but I remember that there was a silence and then I thought that it is a bad thing, but I understand that it is human, and the midwife cried out 'oh my she has a cleft'. It was kind of, it felt bad somehow...
/ and that one did not know much then because they took her away; so I think they could have left her with me for a bit longer so that I could have seen .. I remember that I was terribly worried because I really didn't know if this baby is going to die and is this really hopeless and am I going to lose her..."

and later in the interview:

M: "...I was so terribly expectant and happy and I imagined a kind of a beautiful doll (laughs) that I could coddle and be proud of and show to people..."

I: "Did you feel that this side was left out somehow, that some part was left out, like this showing and things like that?"

M: "Yes it was, and the happiness after childbirth."

The mother of a boy with a bilateral cleft lip and palate, her second child (23):

M: "The doctor just said that he has this (cleft lip and palate) and I knew nothing, and then they gave me this brochure right there in the delivery room. Kind of a, how should I put it, terrible shock...

I: "How did you feel when they brought the child..."

M: "I didn't understand it. Then I just had this feeling that why me (she is crying)... I thought he looked terrible when you think that he had this lump here (pointing at her lip) but one grew used to it soon."

But when I asked her the same question later in the interview (we returned to the birth of the baby three times in this interview), she said:

M: "It was awfully hard to adjust to it, and it took terribly long."

I: "Did you feel opposed somehow, that I don't want this?"

M: "Yes. I said to my husband once that I don't want this baby (crying)..."

I: "What did he say to that...?"

M: "He just said something that made it all a bit humorous, I don't remember how but he said it so well and so calmly..."

The mother of a boy with a bilateral cleft lip and palate, her second child (27):

M: "Well, when he was born the midwife said that don't be alarmed but it seems to her that the child has a pretty bad cleft lip and palate but somehow it is such a relief when a child is born that I was just terribly happy, I remember that I said that it doesn't matter (laughing). My husband has had a cleft lip so it didn't kind of... on the other hand I have often thought that my attitude was in a way too positive in the sense that...that I didn't realize that when the palate is open it is a bigger thing. Well, it then felt bad because the midwife kept repeating that here is a lot of work for the mother and father for years to come and she kept saying that (laughing) and then I asked her what she meant, so she said that she doesn't know from here onwards and ask the doctor...and then came this young woman doctor and I think she didn't know anything about this...and you could see from her that she was awfully embarrassed and she wanted to get away soon."

I: "So she experienced the situation as more difficult than you?"

M: "I think so, when she realized that she didn't know anything about this and she couldn't admit it somehow and she could have said that she doesn't know much about this. Actually, in the beginning at the ward, I didn't feel much pressure and I didn't think--- looked so awful after that because I don't think children are especially beautiful when they are born."

The mother of a boy with a unilateral cleft lip and palate, her first child (section) (22):

M: "The section has started, the first cut has been made and now the water is out and then the boy was born and the midwife showed me at once that he has a born malformation and I saw the cleft lip. At that stage one couldn't really, or didn't understand it at all even though one could see it, and all, but one just lay there thinking what is this now, but I didn't think it was bad but it first occurred to me that I hope he doesn't have anything else...and for example this anesthesiologist who was behind me...he was a young man and he immediately took my hand and stroked my hair and was very empathetic, he didn't say a word though and I had to close my eyes so I wouldn't start crying because he was so friendly. Afterwards I had a terribly bad conscience because I was not at all shocked that I didn't feel like crying but I cried because we had a baby and because it was so wonderful...(but) then at night I cried a lot thinking how it turned out like this and what is going to happen, but not any more in the morning."

The mother of a girl with a cleft palate, her first child (11):

I: "Do you still remember in the hospital when the midwife said that there is a hole in the mouth, so what was your reaction?"

M: "I felt perhaps that I have failed, that hell this is how it had to go as I have failed in everything else, so I failed this too (laughing). That is actually all that has happened, nothing worse than that has happened in my life so far. I kind of took it as a personal failure."

I: "You mean you didn't succeed in giving birth to a healthy child?"

M: "Something like that."

The initial response of most mothers to the news of their child's anomaly was more or less a shock, but sometimes the shock came later and not immediately after the delivery - sometimes as long as half a year later. Usual reactions were tears, disbelief (it was a dream), and questions like "why me?" Some mothers reported feelings of rejection: they did not want the child, they had not asked for a child like this or that "nature should have fixed this" by spontaneous abortion.

But there were also mothers who immediately started to feel protective and loving. One mother of a boy with a unilateral cleft lip (9) and palate tells me:

M: "In the hospital I had this feeling that I could have been torn in two, if only the child could have been healthy. Such a little one...it feels wrong that the little one must have something like this."

Delayed Reactions

Some mothers felt that they did not have strong immediate reactions and that their reactions were delayed:

I: "How did you react when --- was born? Was it unexpected that he should have a cleft?"

M (26): "I didn't really (think) anything then, --- was six months when I first had this..."

I: "What kind, or what did you think then...?"

M: "I can't really say why. Maybe it was only then that I kind of recognized that he is what he is. /... I suppose it is so when you no longer need to feed so often and you can go about your own things in-between and you start to think. No, the feeling came when we were here (at the Cleft Palate Center for the second surgery) and there was a one-year-old boy and I think he was also mentally retarded, I couldn't bring myself to ask his mother, but his behavior...and then I had this idea that maybe --- too and if he has only developed so far and now he will stay in a way, it must have been this incident when I saw the boy here."

Some mothers had an urge to flee:

M (25): "I must say I was very tired. I felt like slamming the door and leaving, I said that I'm going to pack my bags and I'm never coming back (laughing)...

I: "Was this the very beginning?"

M: "It was in the beginning, let's say at 4 months I was quite exhausted, and then it really occurred to me that should I leave this mess and close the door and never come back".

Usually the mothers seek catalysts or reasons for their delayed reactions. One explanation that is offered is that when life becomes easier, the reactions come to the "surface". The mothers have been struggling for half a year or for a year, and when the first surgeries are over, they relax - and now they react.

M (27) : "Many times afterwards I have thought that when at first I was not shocked, it may be that I was, but I made myself go on, to somehow manage past a certain point. At this stage, when the surgeries were almost done, I was awfully tired and I suppose you start to relax some tension...it came as a feeling that I can't bear to stay at home and I can't take care of the kids and actually terrible feelings of hatred toward the kids. And at one time I felt I can't stay home, that I'm afraid I'm going to do something terrible to them, because I'm so tired.

Yesterday, I had a situation here in the hospital when I put --- to bed. Somehow now that it (the child) is better it reacts very strongly when it is tied to the bed, and it went into a terrible rage when I tried to put it to bed at night...so I felt this dreadful feeling of hate for my own child and I felt terrible when I left the hospital, feeling like that toward your own child, and in a hospital at that. It is really awful, and I felt so bad last night, and I thought what kind of a mother am I really."

Another mother (34) felt this way.

M: "But when --- was six months I had a terrible need for knowledge, a need to talk, and a need to accept my own crisis and the anomaly. So it was some kind of a fight. And on the other hand, I don't know, when --- was born all my energy was focused on keeping him alive, but when I started to manage the routine, then I felt the worst rage, or why did this have to happen to me, and a kind of jealousy when I see healthy babies, and this anger, it only came at six months. / After the first day of crying at the hospital I took on a very strong role...the kind of laughing and smiling and you know, I'm going to handle this, but then in the summer I felt weak and somehow fell apart."

But there are also other explanations for delayed reactions. Here we have one mother of a boy with a cleft palate only (15):

M: "For a year I have lived as if --- were healthy. I have learned to feed, and he has had no infections in the ears...I haven't thought about the surgeries or treatments or anything, about his speech or teeth or anything and I have in this way protected myself...When they notified that (--- is going to have surgery) then I started to react, I had stomach trouble and then I lost one kilo and was terribly nervous, I cried and yelled at everybody...but it was only after I heard about the surgery. One started to think about all kinds of things."

Thus, one explanation offered is that when the cleft is severe with several surgeries combined with feeding difficulties, the mother simply does not have time to think much about the cleft and the reaction comes later. But when the cleft is not visible, needs maybe only one surgery and is not combined with particular feeding - or other difficulties, the child is regarded as healthy, the cleft is forgotten and only when it is time for surgery does the mother start to think about the problem and react. Of course, every mother had difficult times during the first year, but a reaction is classified as delayed only if there have been no reports of an immediate reaction.

Depression

When using the concept "depression" here, it is not used as a clinical diagnosis. Some mothers felt that they were "depressed", and I respect that feeling, despite the fact that some of the mothers might have used the word quite easily, while other mothers might have been depressed (as a clinical diagnosis) without knowing it. Postnatal depression is not unusual, and therefore it is difficult to determine to what extent the fact that a mother felt depressed resulted from the fact that her baby was born with a cleft. However, many mothers talked about having been depressed for some period during the first year.

The mother of a boy with a bilateral cleft lip and palate (31) (the boy was tube-fed the first month and came home as a one-month-old baby):

M: "I was quite badly depressed. The period when --- was in the hospital was all right, as I visited the hospital daily and the days went fast, but then when --- came home, I was so depressed I for instance couldn't sleep. I had difficulties sleeping, I just could not get any sleep and I had this feeling, I knew it, it was clearly a depression, I was terribly restless, I really couldn't sleep even though I was tired ..I somehow just watched this child. I was really depressed."

The mother of a boy with a unilateral cleft lip and palate (22):

M: "I got it (depression) after six months, after Christmas...the walls just started tumbling down on me and I had a bad depression and it lasted 2-3 months...it got so bad that I no longer cared about anything else than that the child was ok, I would spend the whole day in my nightgown and then I stopped brushing my teeth and the house was a terrible mess so that my husband always had to start cleaning and stuff like that. It somehow got so serious that it was no longer a minor depression, but then I thought that one somehow gets so isolated, one gets stuck inside four walls when the highlight of the day is when you go out to buy some milk and sausage or check which shop has a special offer on bread ..."

I: "Did you get any help for this depression?"

M: "I don't know, the telephone bills started rising at some stage (laughing) so I started calling people, there were some mothers who were at home at the same time...I considered going to the mental health clinic to talk and I said that if this does not get better I will have to go, but then somehow when it was at its worst, it however quite soon got better after that."

Even though many mothers have been depressed, no one got, or was even offered, professional help for it. It seems to be difficult to identify depressive mothers within the normal nursing-care system, but there is professional help available for families who need help. So far families with infants with clefts have not been identified as belonging to a risk group in that sense.

Envy

There are feelings that are not normally connected with motherhood: Winnicott, Bettelheim, Bowlby and other authorities do not mention envy, hate, bitterness as feelings connected with motherhood. Still, mothers are persons, too. And when a person is disappointed, she might also develop some negative feelings towards other, from her point of view, more lucky people

The mothers felt that this can be hard for other people to understand and to respect as a part of a process that a person might go through. But let us listen to them:

The mother of a girl with a unilateral cleft lip and palate (29):

M: "I had as a roommate (at the maternity hospital) a woman who had had her first child...of course it was jealousy, I felt that everything was so easy for her (breast-feeding), her child was so beautiful, and everything you think at a time like that, and then I was discharged a day earlier because I said that I have to get out, that I cannot bear to stay here.."

and later in the interview:

M: "and the envy...I looked at this other mother and saw her as one big breast, of course there was no difference, but I felt she was different."

The mother of a boy with a cleft lip, her second child, with a previous experience of the sudden death of her first baby (Sudden Infant Death Syndrome, SIDS)(38):

M: "First of course, why does my baby have to die, why just mine, and many people I know have had babies and they haven't died of anything. Or then about --- I remember thinking in the hospital that why our son when there is no-one else in the babies' room who has it, that he has to be different again. I remember I was so angry that I sometimes hoped that someone had something wrong...one is like that (laughing)... so I have sometimes hoped that damn if there could be something wrong when they have the baby. Terrible thoughts, but on the other hand you know it won't have any effect."

I: "Have you talked to your husband about these things, or have they remained your inward thinking?"

M: "I have talked to my husband, for example when his sister had a baby some time ago, that I hope the baby is crippled or something (laughing) .. I think her (the sister's) attitude was a little mean and I really said this to him and he said that one does NOT say things like that, that it is horrible."

The mother of a girl with a bilateral cleft lip and palate, her third child, felt that people were happy about what they saw as her failure. She felt that they (she and her husband) were considered a happy and successful couple and that this had created envy among their neighbors: (34)

M. "It is interesting, this thing about Finnish malice, somehow some of the people rejoice over other people's misfortune... or something like 'poor you, ha ha' (laughing) and they somehow get at you, ha ha you had this accident and that means I'm stronger than you now."

When talking with the mothers, I found it remarkable that they were able to talk about negative feelings in such an open way, since it is not socially acceptable to admit such feelings. In this case it proved that the contact between the interviewees and the researcher was good, and that the mothers felt safe enough to talk about these things. Usually mothers should be regarded as being "exemplary" (Silverman 1989). In this case, the mothers needed to talk about less exemplary behavior and feelings.

Ghosts: What were the Mothers Afraid of

All the mothers, with one exception (the boy was later found to have autistic symptoms and motorial retardation, but this was not known at the time of the interview), who participated in this study had children with solitary clefts that were not connected with a syndrome or another anomaly. Despite this, many of the mothers were, or had been, afraid that their children would have "something else", often a mental retardation.

The mother of a girl with a cleft palate, her third child (20):

M: "I was anxious, I cried a lot and was depressed because I had no information and I started wondering if there might be something else wrong with --- besides this."

I: "What kind of trouble did you suspect?"

M: "I thought maybe there is some structural defect in her mouth or in her gullet and then afterwards I started to suspect that what if there is some mental defect or something else, something in the motion since you cannot see from a small baby, so I lacked everything, all information and the nurses didn't...or I didn't actually even ask anything right there."

The mother of a girl with a cleft palate, her fifth child (14):

M: "it was so that the nurse noticed it and then the doctor hurried, I was on my way to having sterilization, I was under premedication, so the situation was quite suitable for telling such a thing, that the child has this (cleft). And I have sometimes read about this and had an idea that there is always something else too when there is a cleft and I was afraid all year, that there will be something else, if nothing else then some hidden cleft that cannot be fixed in one surgery and that was my fear. But then it was eased by the fact that --- has been walking since she was 10 months and she says several words and she is very strong and high-tempered and I think she is quite well-developed compared with my own previous babies.

The speech therapist then (came to me) and I noticed by what she did that she was not used to this kind of situation, and that it was her job to calm me down. She praised the child and how lovely she is, and I thought that this is something bigger than I was first made to understand. And this thought kept coming back to me from the very beginning, whether she can hear, because I thought that if she has a cleft palate, so there must also be something wrong with the auditory organs, as I work in a special school where there is a school downstairs for children with defective hearing, and they have a lot of these cleft lips and severe speech defects, and I associated these things in my mind and (was afraid) if she can hear."

The mother of a boy with a cleft palate, her second child (17):

M: "They did take a chromosome test and then some other test and then they examined his heart and all this was done already in the premature babies' ward and they found nothing."

M: "Did you personally fear something special?"

M: "Well, brain damage of course is the worst alternative, so I thought what if anyhow. No matter how hard I tried to be sensible and think that he need not have it, but still I thought that it could be, that there is such a possibility."

I: "Did you observe the child yourself?"

M: "Of course I did (laughing). Of course I watched him and listened to the sounds, how they come out but perhaps not so much after I noticed that he was able to establish contact with me and that he can hear, I was thinking about the hearing and at the post-natal clinic when he didn't hear, and he didn't need to then, but I asked the ear specialist (the baby was then six months old), about the hearing because he couldn't hear at the clinic and they said he doesn't need to, that's why I asked, but I understand that at the center it has happened that they haven't noticed that a child cannot hear and a long time may pass, and I think it is sensible to ask. But I knew already at that stage that he can hear, because he heard my voice and all this and when I realized that, then this trouble was forgotten.

I: "How many months was he when you began to believe that it's only this and nothing else?"

M: "I wonder when it was, it would be nice if I had written it down. I suppose it was one month or so. I told my sister and I cried on the phone...(crying)...and then I thought he might have some kinds of defects."

I: "What did she say?"

M: ...(crying)..."Well, nothing, she just said that it need not be such a terrible fault, that there are others who have trouble with their speech or cannot pronounce right, but nothing else, she tried to encourage me, that it isn't so dangerous."

I: "Did you have the courage to discuss these fears with your husband?"

M: "Yes, I said to him that what if there is something, so he (said) there need not be."

As we can see, some of the mothers have been very afraid that the child would have some additional problems. They have been suspicious of what doctors and nurses have said - and sometimes it is the doctors and nurses who awaken the suspicions.

3.1.3 Taking Care of an Infant with a Cleft

To take care of a new-born infant with a cleft palate is not an easy task for any parent, and might be especially difficult if it is their first-born. The parents have to deal with feeding difficulties, with respiratory infections, with surgeries and post-surgical care. One mother of a girl with a cleft palate, her third child, describes the problems (3):

I: "Could you describe a day in your life in the beginning?"

M: "There was a certain rhythm, but I can't remember it any more. It was usually so that first I woke up, if I had slept at all, or I did sleep short periods in between. The first feeding was around six a.m. and then she must have slept and I started milking and after I had done that I woke the elder brother and gave him breakfast and then I think we hurried out and I took him to the park at 9 and then I came in again and fed the baby – and then I milked again and fetched her brother from the park and fed and milked...and so on around the clock. That is...until the evening, until 10 o'clock. After 10 I fed --- and then we slept for a few hours, but then she woke up again at 1.30 to eat...and I think she slept until about half past five, but I did my milking in between, and if I only could have slept those hours...

Feeding and Eating

Most of the problems are connected with feeding and eating. First the baby has to learn to eat and swallow, and then comes the time for eating solid food. The feeding problems vary a lot, but almost every child with a cleft palate has some. Infants with a cleft palate are usually unable to generate sufficient intraoral negative pressure to nurse adequately themselves at the breast. (Davis 1990, 28.)

Besides the factual problems, the mothers have to struggle against feelings of disappointment, because they usually cannot breast-feed their babies. Breast-feeding is the most common way to feed a baby in Finland during the first months, and it is highly recommended. Mothers who are not able to breast-feed their babies for one reason or another, often feel that they have failed in something important that is connected with good mothering.

One substitute for breast-feeding is to extract milk using a breast pump, and most of the mothers tried to do so.

The mother of a girl with a cleft palate, her fourth child (2):

M: "Though there have been moments when I was supposed to use the breast pump, there were more tears than milk...At the hospital I had lots of milk, I just happily carried the bottles like: milk for my girl, but then at home it stopped...there just wasn't any, but then I thought that why should I tease myself, if there isn't any more of it, it won't hurt the baby."

When this mother was talking about feeding she was crying, and she found it very difficult to talk about the feeding problems that she had had.

The mother of a girl with a cleft palate only, her first child, was very disappointed (11):

M: "I remember the brochure said that very few manage to breast-feed, but it also said that if the cleft is relatively slight, it is possible to breast-feed successfully. And of course I wanted to trust that ---'s case is slight, because I had nothing to compare her with, and at the ward they said ---'s cleft is slight, since they said that there are cases when the lips are all broken up to the nose and I think they mixed up cleft lip and cleft palate. So they thought it is really insignificant as it is only in the palate and it would have been awful if it had been in the lip, and they said about breast-feeding, that it will certainly be all right. The doctor who did the dismissal inspection said that it will go well at home, even though I didn't succeed at the hospital and then they gave me all kinds of breast rubbers and they said my breasts are of a wrong type, I'm too nervous, I have eaten chocolate, the milk tastes bad, the baby won't have it because I have eaten chocolate or something. I then tried breast-feeding at home, I asked a friend of mine to come and take --- to her breasts, though she didn't have any milk (laughing), but I wanted my friend to tell me if she sucked right, whether it is the cleft or is it only that I don't have the right technique. One thing I should have done, I should have given her to someone who is breast-feeding herself, so I would have seen that she cannot get the milk from anybody else either, but I didn't do it, I just practiced with a dry woman (laughing)."

I: "How long did you go on trying to breast-feed?"

M: "--- always cried so hard and I started crying too, but I didn't try for very long."

I: "Did you give her anything else, or just the breast?"

M: "I did use the breast pump, I had to do that at the hospital, and I kept on with it until 7 months. Until 5 months she had breast milk only, and then I started to switch over to a substitute when she had her first ear infection."

I: "So how long did you try to breast-feed?"

M: "I cannot say, I don't remember any more."

I: "Then you gave her the bottle?"

M: "Yes."

She did not want her baby to eat with special cleft-nipples, she wanted her baby to eat with normal nipples:

M: "They (the hospital) got one (cleft-)nipple but we didn't even try it and the nurse said that she doesn't think it would be good and I myself felt that it looked so horrible, I didn't want to be so different that my baby would eat with such a terrible looking nipple (laughing), but I wanted --- to eat with the same kind of nipple as all other babies, things like this, I kind of rejected the fact of being different, something that then afterwards, but on the other hand I understand, I many times thought that why can't you eat like everybody else."

I: "How did --- eat, did she have the strength to eat well, or did you have problems?"

M: "(Laughing), I think we kept records for six months on how many grams she ate because --- grew very slowly, so the amount she ate was always very small, but she peed always and the diapers were always wet and she did get enough food and the doctor at the clinic said that --- gets enough food, that I need not worry."

She gave her baby breast milk for seven months, which she found exhausting.

M: "It was a kind of mourning or redemption, I sort of redeemed the whole thing for myself, and it was something crazy, the pumping I mean, then later, and I just went on and on with it and tortured myself, as if I were somehow punishing myself. I didn't realize it then, but now afterwards."

I: "You said you felt shame when you sat by the machine?"

M: "Yes, and my husband didn't like it at all when I was milking, since he had to wash and boil the bottles all the time, because we tried to rationalize the procedure, I used glass bottles all the time, and only afterwards I understood that we could have used disposable bags so I could have pumped directly into these bags and put them in the freeze and then put them in the glass bottle. But all this I understood only afterwards, one did such stupid things in all the hurry and panic and repeated the same mistakes all over again, and one was so tired and up to one's ears in it that one couldn't see it, couldn't act rationally. Terrible fuss and nothing really came out of it (laughing)."

This mother also talks about why it is so difficult to adapt oneself to the fact that breast-feeding is impossible:

M: "And then, like I said, perhaps I poured out my sorrow on him (my husband) about the fact that everything didn't go normally, that I didn't become a woman, I mean a woman in the sense when a child is born, that you are so very much a mother, and then this womanhood or motherhood is such a struggle."

I: "What do you think causes it, why is it so difficult, why can't you think that we will give the baby the bottle from the very beginning, why does one get stuck with it, do you have any idea about that?"

M: "Well I think it's inside you, when the baby comes, in the very beginning when --- came near me the milk started flowing, it is kind of built in and then it's also what you see everywhere, you get the pictures at the maternity clinic, there are no pictures of pumps or (laughing), there are only hazy pictures of mothers with babies at their breasts. Some woman said that they are like that because nursing is so terrible that they try to persuade mothers with this stuff, they try to create a picture that it is very sensible and pleasurable. But I do think it is pleasurable, or I'm not sure it is (laughing) but at least more pleasurable than pumping. In other words, it's both in my biology and then in what you get from outside, what they force on you."

This mother felt that there is a sociocultural pressure that a baby should be breast-fed in addition to the internal instinct or drive to breast-feed the baby. Both of these factors together make it difficult for a mother to adapt herself to the fact that breast-feeding may be impossible. One mother (13), however, struggled for two months to "teach" her baby to accept the breast and finally she succeeded. The baby was her third and had a small cleft of the soft palate:

M: "It started out that I had a very strong need to breast-feed, and our baby has sucked very strongly all the time, he still does, he sucks very vigorously and he would just go on and on. And I gave him the breast and fed him and fed him and then we weighed him to find out if he got any milk, and he didn't and we gave him the milk I had pumped in a bottle...And then we adopted such a habit that after he had had his bottle I took him to my breast and he suckled there and then fell asleep quite content even though he didn't get anything, and we continued like this for a long time. Then somebody here (at the Cleft Palate Center) said that she had heard that some baby with a cleft palate had sucked and then I thought that we will try, but I no longer taught him and didn't try at every feeding, I just gave him the bottle and if I had time I gave him the breast. Then finally he was at the breast once or twice a week. Until once, I remember it was Midsummer's Eve, I felt that now this baby really grasps the breast and he can suck!

I: "How old was he then?"

M: "He was 2.5 months when he learned it, and it really started this one particular time. i cannot say how, and what caused it, it just started and I took the breast pump away and thought that we are going to breast-feed. And we sucked and belched and sucked, so that I had the feeling I have the baby under my arm all the time, but I was very relieved because I didn't need to use the pump. It no longer felt so bad to have tc sit with the baby constantly at my breast, and he got nothing but breast milk till he was six months, and then little by little, he was 10 months when I weaned him because of this surgery, and everything has been fine so far."

But even when the mothers decided that they would bottle-feed their babies, they had a lot of feeding problems: the baby ate very slowly and often and the weight-gain was poor. Another problem arises when it is time to introduce solid food to the baby. One mother of a boy with a cleft lip and palate, her first child, describes this in the following way (26):

I: "When did --- start having solid food?"

M: "At 8 months. I fought with him for 4 months. People sometimes stared at us when we were out, and I had to feed him, so they looked and wondered if that mother is crazy trying to feed the baby against it's will and he is screaming. But I had to, if I gave in I saw the consequences the next day. I kept fighting with him 4 months."

I: "Did you get any instructions about feeding?"

M: "I got some here (at the Cleft Palate Center). At the post-natal clinic they said they didn't know how babies like this were fed and cared for, they told me to call here."

I: "Did he accept the purees quite suddenly?"

M: "Yes. I noticed that --- understood himself how to swallow , because until then every time I got something into his mouth, it came out through the nose, and he started screaming immediately, and then he wouldn't accept it any more, if I tried to force him he pushed the food out with his tongue. But then one day, and I still remember the day, he started screaming when he saw me take the spoon (he hated the spoon more than anything at that stage) and when he saw it he started screaming and I put it in his mouth though he didn't want it and none of it came out of his nose but everything went down and then he opened his mouth for the next spoonful (laughing). So I suppose he understood how to swallow it, since it didn't come out through the nose, and then it started to go right, no matter what I gave him, it just went down...But it was indeed then, and I shouted to my husband: look there is nothing coming through his nose!"

I: "How did it feel after having to fight like that with every feeding for 4 months?"

M: "I danced like an Indian around the house (laughing) and I thought how wonderful that I can finally feed him puree."

I: "How did you cope with those situations, it can be quite infuriating when the baby doesn't eat, even when you know that it's not the baby's fault?"

M: "Every now and then, when he started screaming, I went to the bathroom and counted to ten and came back (laughing), so I didn't retaliate on ---, but I have been in the bathroom many times counting to ten...It was a day of joy when he learned to eat the puree, and it was really a relief when I could throw away the bottles."

Feeding problems were mentioned in every interview, and often the mothers returned to them many times during an interview. With any significant cleft, the feedings at its best will be prolonged, and at its worst extremely difficult and frustrating. Sometimes the child is 8-9 months old before any progress in feeding will be gained.

Surgery

Another problem that may have a significant impact on the family is surgery, including anxiety and uncertainty, separation from the baby, change in the child's appearance, postoperative problems (including behavioral disturbances in the child). When there are siblings, there is the issue of providing care for the normal children when the cleft lip and/or palate child is at the hospital.

One problem is the change in the child's appearance: even if it is desired, it might be a shock to the parents, and might also cause reactions of sorrow.

The mother of a boy with a cleft lip and palate, her second child (33):

M: "It is terribly hard to be here. Of course it may become easier each time, you learn to adjust. I think the most terrible situation is when he comes from surgery, and how he looks and the moment when he comes...it is so terrible...And the nurse...said that this must be your baby and I said it's not (laughing). Then I just stared...and I thought he looked so different, but then -- recognized me and smiled... and of course I started crying...

Last time, for instance, when we brought him here for surgery, I had great difficulties keeping calm, I thought "he's all right like this", because I felt everything was going well, that we wouldn't need to correct it..."

The mother of a boy with a cleft lip and palate, her third child, decided not to stay with her child at the hospital when he had surgery the first time (31):

I: "Have you been able to stay here with --- every time?"

M: "No, not when we came here the first time, I went home in-between."

I: "You left him here and went home and then came for him?"

M: "Yes, or I came a few days earlier to learn to clean the wound and to feed him, but then I went home."

I: "How did it feel to go home then, what kind of feelings did you have, was it difficult to go?"

M: "No it was not. I was somehow so tired of the whole thing, it was a sort of rest for me."

I: "Was it like a relief for you?"

M: "Yes it was, because I could be sure that — was too young to miss me really, a baby of three months cannot miss its mother as long as it is fed and dry and all the basic needs are satisfied, so I had no problem with my conscience. I was thinking about myself, I was able to rest and go out and take care of the house; and my older children had been left pretty much adrift. I went downhill skiing with the family."

I: "But then you apparently decided the next time that you would stay here?"

M: "Yes I did, --- was already 8 months old when we came here the next time and --- was old enough to miss his mother, and I could not have imagined going home, and it was already much easier for me to be here when I had had a chance to rest and all. ---had started to sleep whole nights so I was in better shape too."

The mother of a boy with an incomplete cleft lip, a twin whose twin brother had a cleft lip and palate but who was still-born:(21)

M: "When I came here I thought he (the other twin) was lucky to die (crying) because I thought they looked so terrible (crying hard)."

I: "The mothers themselves also think they look terrible?"

M: "Yes, but I wouldn't have liked him less for that. And what I thought was so awful here, it's how they looked when they had been operated on, and therefore I thought it was good that he didn't need to go through with it, as I would have felt terrible to leave --- here then. And when we came here on Tuesday, when he had had his surgery and we were supposed to come to see him in the evening, they didn't let us see him, and I thought that was dreadful."

I: "What grounds did they have for not letting you see him?"

M: "Well, that he had just fallen asleep and he would start crying if he saw us and recognized us and our voices, but that's what you are here for if you are told that you can come and look. So I think they shouldn't forbid people to see their own child. It was not at all easy the first days, and to know that he has pains and gets a lot of medicines and when you don't know the language here, and I think that's the worst part."

I: "How have you experienced the time here as a whole?"

M: "I think it's been very hard, I really think so, but it's gone all the same."

I: "Where have you been staying?"

M: "I have lived with my relatives in (a town). But it's all right, I have come here in the morning and driven back to (the town) when he has fallen asleep. I think it's been very exhausting, but I have wanted to be here, I didn't want to leave him."

I: "Did you look forward to this surgery, were you even a little impatient, or the other way around, have you thought that there is no hurry?"

M: "No, I have been looking forward to it, ever since the beginning of May, because that's when they called from the hospital in my hometown and asked me and they said it would be either before Midsummer or after it, and they asked me what I thought, and I said preferably before Midsummer, so I have been looking forward to it, and the closer it got, the more nervous I was and it really wasn't nice to come here and see the others."

I: "What was the worst thing to see?"

M: "There was a boy here, he looked like the doctors had been battering him, but apparently they had been working on his palate. He had bags under his eyes and he was black and blue all over and it was something I had never been able to imagine. I think it's wonderful that it's over now...
Then it was also difficult for me to picture for myself what was actually going to happen, I knew that he was going to have surgery, that it would hurt him and he would have to be on a drip, but I didn't understand what my own feelings would be, how awful it would be to leave him. And when they didn't let me see him on Tuesday, I thought it was terrible. Surely if I had been really tough and insisted that I want to take a look at him, they might have let me do it, but because of the language problem I didn't make it, I do know some Finnish but I cannot manage anything complicated."

The mother of a girl with a cleft lip (incomplete.), her third child, felt this way:(30)

I: "Did you feel uncomfortable because they had to go as far as up here (that the cleft must be operated up to the nose though the cleft is only a small notch in the lip), did you have the feeling they will mess up something that is unbroken?"

M: "Yes."

I: "You would rather have had them stitch the notch down here?"

M: "Naturally, because the scar would have been much smaller, I thought, because I didn't know what the scar would be like, but it was like a T or something. I left her there in the evening, OK she was quite all right then and all, but then when I came back the next day in the evening after the surgery and saw her tied to her bed, that was the first shock. And when I saw her face, it was so swollen, and there was dry blood and the stitches were there, so she didn't look like herself at all, we were quite shocked both of us, we thought this is not our baby, she didn't look like this when we left her here, but we got used to it quite soon. But it must have taken one day."

I: "Did you think she looked worse?"

M: "Yes, of course, because she had such terrible, or because this part was so swollen, and then the stitches, it looked so bad, and she had only had a little notch here (pointing at her lip), so that's why I thought why do they have to make it so big?"

I: "Did you ask somebody why they had to?"

M: "Yes, I asked before the surgery and that's when the doctor told me they are going to go up here and I asked why do they have to cut so much, so he said it's these here that will pull it up, so they cannot just stitch it together, but have to let them come down so it will look good, but that didn't help, we were shocked all the same."

I: "Did you feel that this shock after the surgery was in some way worse than when she was born?"

M: "Yes, that's just it, she looked quite awful after the surgery, compared with how she looked when she was born. But then when the stitches were removed it's clear it looked so fine that it was easy to get used to it, as I was there all the time, or shall we say during the days, I walked around with her all day. It was quite good to get to know the other mothers, because they all walked up and down the corridors for a week and so you had someone to talk to and ask questions of and everybody talked about their own experiences."

I: "You were with her at the hospital, do you think it was hard?"

M: "Yes."

I: "Did you get any help, did your husband visit you?"

M: "Yes, he sometimes came in the evening, but I thought it was better if he goes home and takes care of the others. My mother cared for the older children during the day, and then my husband in the evening and I thought it is easiest that way, of course they came in now and then to see us, but I was alone most of the time. What I think was toughest,was that I had to walk around and carry her all the time so she would be occupied and wouldn't start sticking things in her mouth, which was what she most wanted to do at that time, and so I had to walk in the corridor and I think my footprints can still be seen there (laughing)... And I was so exhausted having to carry her all the time, and one had a bad conscience because one couldn't leave the baby here, one just couldn't, only when she was sleeping could I go out and eat something or breathe some fresh air, and then I had to hurry back again... it's the typical mother's instinct (laughing) ...but it was hard, yes."

She fell once only a few weeks after the operation and hit her lip, and it hurt me so to see her hurt, it was terrible, but that was the only time she tumbled, she still couldn't walk then, but she just somehow fell over, I don't remember, right on the floor. I was pretty anxious after the surgery about how we could watch over her all the time so that we wouldn't get anything in her mouth."

The mother of a girl with a cleft lip, her second child (39):

I: "The surgery changes the appearance dramatically (laughing), how did you experience the situation when you went there for the first time after the operation?"

M: "(Laughing) that it's not my baby (laughing). It was really, she looked so good, she looked so exciting, it was really a pretty fantastic feeling, I couldn't trace any of her own looks there. It took a while and then I got used to it."

I: "Did you even go and check?"

M: "(Laughing) yes (laughing) yes we did, and then because she was quite bloody, so she was a little... but otherwise she was quite, not even very swollen then but on the next day she was a bit swollen and then she had this band-aid (laughing). It was a little like the whiskers of a bunny rabbit right here."

I: "What kind of feelings did you experience when you saw --- there with the band-aid?"

M: "Well, I don't know, maybe it was that you always... it's just because she was so ill, I felt so sorry for her, but it was nice to see that the surgery was so successful, it really was, and they do a very good job there, it is unbelievable what they do. But it's like that, to be quite frank I can't explain the feeling. In a way you feel very good and think it is very good, but then you feel so sorry for the baby because it hurts so bad, and it is a very mixed feeling."

I: "Had you been looking forward to the surgery or were you afraid of it because many people told you contradictory stories about it?"

M: "Mainly I, I had this feeling when I was supposed to take her there, and the closer the time came, I kind of thought I won't take her (laughs), that I won't take her because they are going to hurt her, this is what I felt all the time. The closer the time came, the more worried I became about it. . and then when I had to take (her to the surgery) and when they took the tests, we kind of panicked and we really had to take hold of ourselves, so I wouldn't run out the door with my daughter, I thought I really won't take her there, but then it was over. Well, the first night I couldn't bear to look at her, I couldn't stay there because she was so ill, but when we went there the second day, well they told us we shouldn't stay long on the day she had been operated on and she cried so hard when she saw me..."

So the surgery, even when it is desired, is often a chock to the parents. They have to get used to their child's new appearance. Some mothers felt that the surgery gave them a chock that was worse than when the child was born. And sometimes the surgery is not even desired, it is just something you have to go through. The descriptions some of the mothers gave of their own feelings were also striking: they feel the pain, when their child nurts himself.

One mother (10) got desperate when the surgery did not succeed and had to be done again:

M: "The lip was torn and he was screaming... and I ran out, I went to the park and I cried and I thought I'm going to kill this baby."

For this mother, the failure was too much for her to bear at the moment. But she was able to handle these feelings and she was a loving and caring mother.

To this study was added a mother of a girl with a cleft palate, her second child, who was over two years old before her cleft palate was repaired (normally the cleft palate is repaired around 9 to 12 months of age). She had been called for several times, and the surgery had been scheduled to happen when the girl was about 12 months, but the mother kept postponing the surgery. She tells about her feelings in the following way (35):

I: "How has --- herself managed the surgery?"

M: "Very, very well, and she has adjusted very well to the ward and everything, even though her hands must be tied to the bed at her age, but she has adjusted very well."

I: "Apparently you have both been able to stay here?"

M: "Yes, we have both been here. My husband is on winter holiday and we even arranged for our older child some days free from school. And we have been here the whole family."

I: "It must be easier too when the whole family has been able to be here?"

M: "Yes it has, but I would still say that it has nevertheless been a hard time for both of us, it's no use pretending that it's nice and easy to be here. I told everybody when we left (home) that I know it's going to be a hard journey. And now that I have called them I have said that I didn't know it would be this hard. Naturally one is always anxious for one's own child. On the day of the surgery i walked along the streets of Helsinki (laughing) and I felt all mixed up and I was terribly nervous all the time.

Though we are here with --- all day, and she only needs to be alone for a few hours at night, nevertheless I've been here every morning at 5.30 all fresh by the bed (laughing)... and the nurses too they always laugh and say there's nothing to worry about, that --- has slept well all night (laughing). And I told the nurse this morning that it just happens to be so, you can't help it, maternal love is such that you can almost walk on the walls for your baby (laughing) if you have to. And I said it may very well be that there's nothing to worry about here, it's the mother who is worried."

I: "Were you nervous before the surgery, was it frightening?"

M: "Yes I was nervous, I was so terribly nervous, and one girl from my hometown had been here a few months ago for surgery and her mother gave me some very negative information about the hospital and this ward. I was told that parents are only allowed in the ward at certain times, an hour or two at a time, and then they have to leave and the children are tied to their beds. And of course I thought they are held here all day tied up and screaming. And then I started to imagine all kinds of things, even more than I had before, hearing stories like that. I was in panic all the way here, and I wondered what kind of institution this really is, but all the information I got from this person was wrong, and I do intend to straighten her out when I go home."

I: "So you are in a sense positively surprised?"

M: "Yes, quite positively, and I want to thank all the nurses and surgeons and everybody, and I think it has all really been very good."

I: "How did you contact this mother who had been here with her daughter?"

M: "Through our neighbor who is related to this woman. I kept thinking about it and thought what if the surgery won't succeed. And it occurred to me, my God, what if she dies on the operating table and all those kinds of thoughts and I was in a panic, but then I thought, well, if God has given her, if that will happen I will just have to accept it. You just have to accept what the day brings "

I: "In other words, you saw the surgery as a risk?"

M: "Yes I did Now that I have been thinking about it afterwards it was a good thing, and especially knowing that her speech would have been essentially worse

> But when I saw them bring --- from the operating room I started crying so hard because the tension eased and I said to the nurse I'm sorry, but she just said it doesn't matter and it is natural that the tension relaxes. It looked so horrible when she had a drip-feed bottle and all, but I saw that she was breathing and she was alive and so the tension eased and I thought thank God it's all over."

Her hesitation is easy to understand in this light. For people with no experiences of this kind it might seem odd to hesitate to repair the cleft of one's own child. From the mother's point of view it might however be a choice between a child with a cleft, or no child at all, a choice between life and death. This may not be a realistic choice *de facto*, but from the mother's point of view it certainly is.

3.1.4 Impact on the Family: Relationship between Parents and Impact on Siblings

It is no doubt quite stressful for the parents to have an infant with a cleft. The total number of different problems regarding the child may be enormous, including great anxiety, and demanding a considerable amount of time, especially during the first year. This can strengthen the relationship between the parents, but it might also lead to the opposite. When there are siblings, they need attention, too, and they might suffer more from the situation than the child with the cleft.

Impact on the Relationship Between the Parents

The mother of a girl with a cleft palate relates her story in an interview that I felt was very deep and sincere (11):

M: "I don't remember how he (her husband) took the situation (when the baby was born), somehow I feel that he still hasn't realized it, like what has happened to---. Now too, when he came here to see--- here at the hospital, I had the feeling that he is the principal character of his own life, or that there are no other leading roles besides himself. We are in the minor parts. In some way he couldn't handle the fact that --- is ill, that--- cries and that he should leave his own worries aside for a while. He was nervous and left because he couldn't stay here. Do you understand?"

I: "Yes, I understand what you mean... he couldn't bear it that--- was feeling bad?"

M: "Yes."

I: "He felt more sorry for himself than for ---?"

M: "Yes. But it has been like that all the time. We are not doing too well, I mean we haven't had the energy to take care of our relationship, and now we have thought that--- and I will move out. Though it is in a way, it's not ---'s fault and it's not the cleft, though maybe if--- had been healthy, it might have gone differently, but it's no use speculating. But my husband feels that all the time he spends with the baby he is sacrificing himself, that he's not getting anything from it, that he has been obliged to leave his hobbies which he likes very much and has to stay home a lot. Or he feels that he has to do housework in the evenings and weekends. He has always been a creative person, he has all kinds of things going on, everything takes a lot of time, he needs a lot of time of his own, so we have thought it would be better so his life would not be ruined, even though this difficult period is not very long, soon-- will be on her way and waving as she goes, but all the same he experiences it like that."

I: "Have you thought the separation would be permanent?"

M: "We are not going to be officially divorced, we will arrange it so that if the situation changes, we can still live together. We are going to live in two places, we have always lived that way, we have had two apartments, so it's not really any loss, it's not so dramatic, we are just living in two places...

But the truth is, maybe we won't move together anymore. This has been a very hard year for our relationship, and also I have somehow blamed my husband for the fact that my appearance, my whole being is not what I thought it would be when the child is born. That I was ugly and awkward, he didn't want to make love with me any more, he hated the milk coming from me and everything about the feeding and all that and it was so terrible. And afterwards, when I wasn't nursing anymore, our lovemaking didn't work out at all... or even if we were in bed and everything was going all right I might suddenly (say) 'yes you hate me, you said so once, you hate me and you never want to see me pregnant again', or 'I never want to go through the disappointment again when you say YAK, milk'.

My husband hates all fat people (laughing)"

I: "You are not fat?"

M: "Well, I feel like an elephant (laughing)."

I: "Do you feel it through his eyes?"

M: "Yes, that's it (laughing)."

I: "How did he respond to your accusations or when you vented your anger?"

M: "He thinks, I don't know if it's true, that most men hate the milk period, I don't know if it's so...But I don't know, maybe that's something I ought to discuss for instance with my sisters, how they experienced it, it need not have anything to do with the cleft or the baby or the breast pump, but it may be something perfectly ordinary that just gets mixed up with it."

I: "So you feel your husband really reacted negatively to your motherhood?"

M: "Yes, and then we have it confused in the way that I feel because it didn't go normally, I mean that--- couldn't suckle the breast, we had so much extra work to do a normal family doesn't have, that my husband is somehow disappointed with me, that I have done it somehow...that another woman would have done it differently.

But I have thought that I hated myself and my physical appearance and have blamed my husband for it, that he doesn't want me, though it was I who hated myself".

This mother was very reflective. No doubt, she was very disappointed about her husband's reactions. She felt that he had not been supportive in any way. She also said that she felt that this interview was very therapeutic for her, because she could talk about these things for the first time.

Another mother of a boy with a cleft lip and palate, her first child (22):

I: " At the maternity hospital, when your husband came in and they brought the baby, how did he react?"

M: "It took quite long before he accepted it, and he didn't want to go out with the baby, for instance when we went shopping, it was very difficult for him. I don't know if it was right or wrong, but I forced him and said that our baby is like this and that won't change, and now we are going to the shop. He came, but it was hard and I knew and understood that one shouldn't be ashamed, and I just made myself do it. For him it was... he was very much looking forward to the second surgery, so everything would be over, because it is so horrible: when it's in the face it causes so many reactions."

I: "If your husband has taken it harder, has it somehow driven you apart, or has it brought you together?"

M: "Before the baby was born our relationship was a little strained because we had moved and my husband moved from the North to another town, everything was new and strange for him, and we had been trying to have a baby for a long time, we had tried for almost a year, and then when I finally got pregnant our relationship changed and then even more after the baby was born, and it sort of united us, he leaned on me and I leaned on him, so we gave each other a lot of strength, and because our attitudes were different we learned to understand the other point of view. My husband became a little softer when he saw that I'm so blind to this child, and as he was more critical, then perhaps I too realized that it was going quite well. We have been here together for all three surgeries and my husband has taken time off from his work to be able to be here with us."

I: "It must have been a relief?"

M: "Yes, enormous. I'm so sensitive that especially here at the hospital I get very tense, and if I didn't have anyone else, I'd be a nervous wreck and I need the support he gives me."

She felt that her husband had been supportive, and he was also eager to take care of the child:

M: "My husband stayed at home very much and participated in the baby care, he still does, and he is a very active father, so that's why I managed so much better when he did almost all the night feeding. I was able to rest and I was in a terrific shape, I wasn't physically tired."

I: "You were able to sleep during the nights?"

M: "Yes, and I could go to the gym and go out for a walk and he always told me to go out a little and visit my friends, and he said that he would look after the baby and I think he was very anxious and very concerned and that helped a lot. I'm sure I wouldn't have been able to make it if I had a different husband who would have left everything to the mother, and I wouldn't have managed, because it does strain your mental energy all the same."

I: "And the baby let his father feed him?"

M: "Yes, there was no trouble. And I didn't even urge him to feed or to change the diapers, he was just so eager himself, and he already was at the hospital."

I: "The fact that his reaction to this was stronger than yours had no effect on the (father-child) relationship?"

M: "Not at home, only in relation to the outside world, and he worried more because of it, but it had no effect on the father-child relationship, perhaps it only made it deeper."

In this family the relations were now better than before the birth of the child. Some mothers, however, felt that the birth of the child had not changed their marriage at all:

I: "Have you felt that this thing has pulled you together or set you apart, or do you think there is no change in the relationship?"

M: "Not actually, we have always been a well-balanced couple. What sometimes annoys me is that I'm so tied up with---, because my husband is afraid to feed the baby, and only now that --- has started to eat well, I'm not so tied down anymore but up to now I have always fed ---, and I'm really sick of it, and we have had disagreements because he didn't want to feed the baby and I haven't been able to go anywhere because the intervals between the feeds are so short and there have been quarrels because I've been so terribly tied to ---"

Impact on Siblings

How then do the mothers describe the impact this event had on the siblings? If the siblings are in pre-school or of school-age, it might have an impact both on their position in the family and on their relations with their peers. For very small children, the problems are related to the attention and time they can get from their parents and to problems connected with possible separation from parents when they are with the clefted child at the hospital. For parents it can be very difficult to solve the problem with conflicting interests in a family.

The mother of a boy with a cleft lip and palate, her second child (32):

M: "--- (3 years) got a stomach disease the same day we came home, and it was quite severe, it lasted three days... the stress somehow came out.

We have explained to --- what it is, and she has had a very nice attitude. We have told her that the baby is going to have surgery and she can come here to visit him. she is of course waiting anxiously for us to come home. --- even plays that her doll has a cleft, and they go for surgery..."

When there are siblings of school age, the problems might be different. A mother of three children (ages 13, 9, and a one-year old girl with a bilateral cleft lip and palate) told me the following story (34):

I: "How about your older children, did their friends react, did they come to your home, was there something exciting about it? Did your children find it difficult to ask their friends to your house?"

M: "No. I was first afraid they might be teased at school. And one of my daughter's friends, when she had her birthday, it was an awkward situation, there were at least twenty girls in the house, and then she just (said) that --- has something wrong with her lip but it will be repaired, period. And then she very proudly came to show them when --- woke up in the bedroom, she told them to come and see her baby sister and the girls came into the room, there was a terrible noise, and my daughter could see nothing awful in the defect... then one of her friends said 'phew, so disgusting', and she had already thought at home that she was going to be sick when she saw it, and I felt like hitting this girl right in the face when I saw my daughter's look. / But it then turned out that this same girl now almost lives in our house and takes care of --- and pampers her... it was just her first reaction, and on the other hand she was being quite honest."

Situations like this can be very difficult to handle, both for the parents and for the children. If the older children note that their parents react very strongly to such events, they can start to protect their parents by not telling them about these events.

The Relationship Between the Mother and the Child with a Cleft

The first reactions have been described as sorrow and mourning, sometimes combined with wishes that the child would not have been born at all. But how do the mothers adapt to the situation? For how long do they have feelings of rejection? Do they love their child when the child is about one year, or do they still reject their clefted child? Let us listen to the mothers and their feelings:
The mother of a girl with a cleft palate, her second child (1):

M: "I must say I have loved --- much more than our first... It has meant a lot to us that she was born, I have always been an impatient person, I just told my mother who has come here from my hometown, that I have become very patient with ---, she has developed my patience a great deal... in the beginning, in the first months I was of course nervous and sometimes almost blew my fuse, but, well I wonder if I sometimes shook her and shouted 'be quiet, what am I going to do with you' (both laugh) and why are you screaming, but... it also must have been a relief to find out that there was nothing else and she is growing normally and everything has gone so well... --- is so dear to me, I do understand the families who have many children and then have a handicapped baby, that the handicapped is most dear to them... one does fall for a child like that..."

The mother who was expecting twins, one of which was still-born. Her first-born, a healthy girl was 21 months when the twins were born (25):

I: "How did you take this with ---, that he had a cleft in his lip?"

M: "Well, it was so small that he was just... and when they told me that if they had waited to the next day with the Caesarean section, he would also have gone... so he was my everything, and he is now too, he means more to me than his sister. I don't know if it's because he lived and he also could have died, that I don't know."

and later in the interview:

I: "You said that --- is terribly close to you, is this something that came right from the beginning in your relationship, that there was immediately a bond between you, or has it developed during this year?"

M: "No, he was (close) already in the beginning, because I was very anxious about this sudden infant-death at the time, it is possible until the child is 8 months, because I heard that it really can happen when the child is as old as that, so I was sort of, I had to look at him once in a while, while he was sleeping. The only thing that surprises me is that I could sleep at night, I slept very well actually. I did not wake up and I wasn't nervous, but in the daytime I was very anxious about him and I wanted to look at him and when somebody else was looking after him I told her to touch him and check if he is alive. I think that during that time, until he was 8 months, he was as close to me as anyone could be. His sister isn't less close, it's just that she has been slighted because of ---. I try to be enough for both of them.

The mother with two children felt this way: (25)

M: "Let's put it this way, that they are healthy children, but nevertheless a little different, I don't know if you grow more attached to these babies because there is more work... probably it's because the maternal love is so much stronger that you want to hold on to it more. I sometimes have to ask myself 'just a moment, is --- different to me than his sister'. You see, his sister had nothing, so somehow I pay more attention to ---."

I. "You feel that your relationship has even intensified because of this?"

M: "Yes."

I: "And it may have something to do with the cleft?"

M: "Yes, that's how I feel, and I have realized that it is because I have had to do so much more for --- than for his sister. His sister has always been an easy child, only now that she has her three-year-old negative stage has she started protesting against things. With --- I have had to stay awake nights and all that, I think this has strengthened our relationship. It is now beginning to balance out, so that they are both equal, but there was a period when my protective instinct for --- was so strong, that I had to hold him so

> nothing could happen to him, I really kept him wrapped in cotton. And I had to discuss this with myself, that it cannot be like this. This is something that parents have to discuss with each other and above all with themselves, and I at least have had to work very hard to reach a balance."

These mothers all felt that it was easier to love the child with the cleft than it had been to love their healthy children. When the child with the cleft is a first-born in a family, the setting is different. This situation is often considered more difficult for the parents. On the other hand, these parents have no previous experiences to compare with.

The mother of a girl with a cleft lip and palate, her first child (24):

M: "But I didn't thing about it like that, I thought she's my own and that's that, we'll have the surgery, and nothing bothered me or made me ashamed or anything. She was still so wonderful."

And another mother with a boy with a cleft lip and palate, her first child (22):

M: "Afterwards I had a terribly bad conscience because I was not at all shocked, and I didn't feel at all like crying, the only thing that made my cry was that we had a baby, and how wonderful it is. But I never had, not even afterwards, a feeling that I should be somehow upset about it... I was just terribly proud of the baby and that was the most important feeling anyway."

The mother of a girl with a cleft palate, her first child (11):

M: "I do think that I have tried, or that I have escaped everything by sticking with the baby. I know I'm ridiculous clinging to her like this, because I don't trust them (the nurses), I dare not leave her with anyone but sit here myself all day and all night, I actually came on Saturday and now it's Tuesday, it's like I were in a prison with her all the time. When they did this section here in front, they had to give her an anesthesia and there were a few hours when she was asleep and I couldn't go there, or I couldn't be with her, so I walked into the forest behind the hospital and there were flowers in the forest, and I picked them for the nurses in the ward, and it was the first time I felt I was free somehow.

> I have drawn the circle myself, my own prison, and I can only come out of it myself, if I want to, but I can also stay there for the rest of my life. But I believe I'm so smart that I can get out (laughing), but whether I'm going to do it all by myself or turn to someone for help is another thing...

Then you live in a dream world, build relationships in your imagination which are not real, you live through them in a way, but I don't know if it has anything to do with this, I think I have always had it, that I kind of build something nonexistent to stay alive."

I: "You look for something through them?"

M: "Yes, or I live in my own imagination, you see, like Woody Allen (laughing).

I: "Have you, however, been happy about--- in the way that you have enjoyed being together?"

M: "Yes, a lot. "

I: "That has been there too?"

M: "Yes. It is no burden, and I have always said that no one has ever been so close to me and such a good friend as --- is, I like her enormously, but somehow I cling to her so much, and I'm afraid I'm going to restrict her life... that I concentrate on her so smotheringly and think I'm doing her good when I'm present all the time. And it could turn out exactly opposite for --- . She may become very shy, or if she is shy I may add to it."

Having More Children

According to Spriestersbach (1973), having a child with a cleft might have some depressing effects on the plans of the family for additional children, but that the effect is by no means extreme. In this study it seems clear that the mothers think about having more children more carefully than they would without the experience of having a child with a cleft, but they come to different conclusions, depending on their life situation as a whole. Sometimes the mothers think that they could accept another child with a cleft, but they are now more afraid of other things that the baby might have, such as a mental retardation or a severe handicap, and sometimes another child with a cleft seems to be very difficult to accept.

The mother of a girl with a cleft lip and palate, her first child (24):

M: "Naturally you think that you don't want this to happen with another child, but I do intend to have more children. It would be nice to know the probability of having another one, and if it could happen easily, but I will have at least one more baby."

I: "And if you have another baby and it would also have a cleft, how do you think you would feel about it?"

M: "Well, on the one hand it would be easier, but on the other it would be as bad because I know what we would have to go through, but I would know how to take care for it and all (laughing), everything would be so ready."

I: "Are you afraid of it, or do you think the sorrow would be greater next time when you know what you would have to go through?"

M: "Yes, it might be, since you know what it is and how the baby will suffer. But I hope not."

The mother of a boy with a cleft lip and palate, her second child (28):

I: "Have you thought of having more children?"

M: "Definitly not. A few years ago we might have said that we'll have one in 10 years' time, but I don't suppose I will, because it's in my mind like a nightmare that the baby could be handicapped and then we would be tied to it for the rest of our lives. Now that these two won't be needing diapers soon, and we can start enjoying the situation, travel and everything.

It is possible that I get a terrible urge to have another baby, but will it overcome the fear inside my head of the handicapped baby? I doubt it."

I: "So the cleft hasn't actually inspired a fear of a cleft, but of some other handicap?"

M: "No, and that's good, so if --- sometimes thinks whether he is going to have babies with a cleft, I can very well tell him to look in the mirror to see if it's even worth thinking about it."

Another mother of a boy with a cleft lip and palate, her first child:

M: "I have knowingly avoided the subject, I don't think that the other one will be, but somewhere in the subconscious it keeps haunting me, I have had a lot of dreams that the other one has a cleft lip. But it's there all the time in the background and I wouldn't like to go through it again, though I would surely do many things differently and I would have a different attitude and now I would know what to do. I'd know how to be with the baby, but still I wouldn't go through this hassle again, and now it would really take a lot of strength.

I: "You think the sorrow would be greater if it were repeated?"

M. "I think it would be even worse if the other one would be. It's terribly difficult to say, but thinking about it beforehand, and if the second child would have a cleft, we surely wouldn't have any more babies, and that's absolutely clear.

> Already we consider if it's worth it and whether we have the courage to do it."

These statements were all given when the child with the cleft was about one year old. Plans for the future is one thing, what actually happens is another. The mother was already pregnant with her second child at the time of the interview. Another mother who was quite sure of not having more children, wrote me a postcard after a while where she told me that she had had a healthy little girl.

3.1.5 The Family in a Social Environment

A newborn with a malformation is a staggering event, not only for the parents, but for everyone else who has shared the event. However, as described in the introduction to this work, responses of human societies to malformations are not uniform, and may range from protection to exclusion. Even within a society, people's responses vary a lot.

Consequently, even if the parents themselves may adapt easily to the new situation, the same family may have to struggle against a lot of problems caused by environmental reactions from relatives, friends, and neighbors - and even from total strangers. In a small village, the baby can become one of the sights of the village. In another village, the baby is seen as a punishment from God. Some relatives cannot handle the situation at all and start to blame one of the parents, usually the mother. In other families, the reactions are mostly supportive and make the relationships between relatives and the family even closer than they were before.

When the cleft is not visible, that is, when it is a cleft palate only, the parents have to decide who they will tell about the cleft, and when. They have the possibility not to tell anybody about it, and some parents decide not to. Others told some people, but not everybody. And some mothers tried to conceal the information even from their own husbands. Many mothers also found that people were very curious about the cleft.

The mother of a girl with a cleft palate, her fourth child, told me about the reactions in her neighborhood (2):

M: "I have had...mother has brought us food, so we have had help and this kind of thing unites if the atmosphere is good, like in the village if something happens it finally brings people together and everybody wants to help. But I noticed that a lot of people came to visit us out of curiosity. People that never (visited us before said) 'oh, you don't even notice it', when they peeked at the baby... they had thought it was a complete (cleft)... so there was such curiosity."

I: "And how did you respond...?"

M: "I was tired, I didn't care... but I should have said straight out that I don't have the strength to receive guests, but I never said anything..."

I: "Did you find it difficult to tell your relatives and friends when somebody called you or something?"

M: "Yes it was in a way /... you see when I had to explain to people, it was hard and I thought 'oh no, what am I going to tell them', but then there was this mother of five in the bed next to me and she said I shouldn't tell anyone at this stage. And somehow it kept bothering me that it's not good so... but then I thought about how to tell people, like when we went to the congregation to receive their blessings, I wondered how we could tell them, as there are all these old people there who will start going 'oh dear, what's wrong with her'. But we just told them that she's a little ill, and didn't talk about the cleft, but it is true that when one knows, everybody knows. But there was this something, I don't know how to put it, you tell me... (laughing).

But then the grandparents said we shouldn't tell anyone, so they felt it should be told..."/...

I: "Did they try to find a reason for it...?"

M: "Well, my mother-in-law said there hasn't been anything in their family (both laugh) and my mother said there hasn't been in her family or at least she doesn't know of anybody (having a cleft) and my father said not in his family either, but now I saw my mother's cousin this summer and both their children had, and I told my mother they have had it and mother said she didn't know, that she has so little to do with them... so it does run in the family... but it's funny how they take it when..."

I: "And the attitude of the neighborhood, neighbors and friends, how have they reacted?"

M: "Well, they have comforted me a lot, they say it will get better, God will heal it. Many have said they have had a vision that God will heal... but it is caused by their will to give consolation...But I knew I'll have to come here for surgery and... and the neighbors, when they heard, they have knitted socks for me... and they are like that, very close, like 'should we bring you something from the shop'.
And things like 'why to you?', and they have been following our life and they say 'you have lived a decent life by any standards, why to YOU?', like this... so I tell them it's not measured, everybody gets..."

I: "Did you feel they meant... it was a punishment?"

M: "Yes, something like that."

I: "And you?"

M: "No, I felt because I have a very close relation to God, he gives me this to make it still closer, something like that..."

This mother was from a small town with the strong influence of a particular religious movement. The cleft was seen either as a punishment from God or as something that could make the relationship with God even closer. Some neighbors believed that the baby would be healed in a miraculous way. At the same time the cleft was seen as a stigma, a stain, and the very fact that both of the families (both on the father's and the mother's side) had a previous history of clefts was denied. The mother found it very difficult to talk about these things, and she cried a lot during the interview. However, the family was strong enough to resist the influences of their relatives, and had decided to talk about the cleft to everybody they met, including strangers.

The mother (of a girl with a cleft palate, her third child) talked about the reaction of the father (13):

M: "First my husband said I must not tell others because it doesn't show, but then our friends started asking why I use the pump, why she's on the bottle, so I told my husband we cannot deny it... and I didn't understand why we couldn't have told them, and I still don't."

The mother did not conceal the child or the cleft, but prevented other members of the family from reading the booklets about cleft that she had got from the hospital (34):

M: "I had a different reaction when this happened, I didn't read the booklet right away, I kept hiding it so the children wouldn't see it but then our firstborn who had come to see us, the 20 year old, found it anyway, or saw it in my hand when I had just got it from the doctor, and said 'AHA, is --- a clefted baby?', like a joke, and I started to understate it, I denied it and said at least it's not as bad as they say here. That was when I was at the hospital and didn't really know what to do about it."

I: "Did you find the booklet frightening?"

M: "Yes. "

I: "In what way was it frightening?"

M: "I think it emphasized, or did I read it that way, the most serious cases, and that you really need a lot of patience and a lot of treatment to make it better and that it is so painful to get the speech right, if at all possible... But the most painful thing is if you have caused it yourself."

I: "How long did you keep hiding the booklet?"

M: "I still haven't shown it to anybody at home, because I just saw there how big it is, and I have had to tell the children and my husband that it's not of much importance, that it's not a big thing and it can be cured. I have seen to it that no one has got hold of it (laughing)."

This mother was afraid that the girl would have some additional problems, and she had decided to keep all her fears to herself. She also blamed herself for her daughter's cleft.

When the child has a visible cleft, it is impossible to conceal or deny it. But one can still choose between keeping the baby at home as much as possible or to take it everywhere, such as to stores and restaurants.

The mother of a boy with a bilateral cleft lip and palate, her third child, considered it very difficult to take the baby anywhere (31):

I: "Did you have the feeling that you didn't want to take --- with you to the grocer's and such?"

M: "Yes I did, I didn't for instance push --- much in a pram around town because I thought if someone comes and wants to take a look at him and might be surprised, so I haven't pushed him for a long time, I only started now in the summer, and I still haven't taken--- to the shops, I have thought we get the surgeries done. It was also hard for me, what the other people think, this is a pretty small town and the people like to talk."

I: "How have you taken--- out, do you have a one-family house?"

M: "We live in a terraced house. He's in our own yard. I have pushed him and have had to, also because of his ears we have to go to the doctor a lot, of course I do, but I don't exactly show him off. It is still a difficult thing for me."

A mother of a boy with a unilateral cleft lip and palate describes it this way (32):

M: "Of course I was sensitive about it when I went shopping, for example. I turned his head the other way if he was sleeping, so that the good side was outwards, I was terribly sensitive and I thought everybody's looking, though people might pay no attention at all..."

A mother of a girl with a bilateral cleft lip and palate, her third child (34):

M: "The situation was such that I had to give therapy to my parents..."

I: "So instead of getting support from your parents you had to give it to them?"

M: "Yes, I had to give them support. My sister of course and her husband had a different attitude, so I got support from them."

I: "How did you mother and father react?"

M: "Mother called me very often, and she kept sighing 'so terrible, so terrible', I can't really say, but she just kept saying it's terrible and her voice was shaking... in the beginning she just cried but she cheered up, I guess my sister had told them to control themselves and not call me and cry on the phone "

The family lives in a small town

M: "Where we live, it's a small town, and we are really famous there and they stare at us. /...The mother at the child welfare clinic came and asked me before the lip was repaired that 'good heavens, what's wrong with her', though she is herself really fat, and I must say it felt a little bad."

I: "Did you feel, when you said she's fat, a kind of counterreaction, like 'why are you staring, you are not so terribly beautiful yourself'?"

M: "Exactly, and inside me I thought that she's really a .., well, never mind, and her children are too, if we are honest, quite ugly. At home I unburdened my heart to my husband, I said 'damn, they should look at their own kids, as they are really a bunch of overfed piggies (laughing a lot), I mean I didn't say that to her, but I felt better for it "

In one family, the father had a cleft lip and the mother (27) felt that when her son was born with a cleft lip and palate, it was a factor that brought her and the relatives of her husband closer together, with one exception, though:

M: "From my husband's side people came quite normally to see us, and nobody said anything, but the only thing was that my husband's brother's wife said she didn't want to see him, and until today she hasn't visited us. That surprised me because I have shown --- in the very same way I showed his elder brother when he was small, and I never thought anyone might feel bad about it, and I didn't even think about it, but this case was such that for the first time I started to think about it, that it could make someone feel really bad."

I: "Did you have contact with your husband's brother's wife before?"

M: "Not really, we have actually just been distant acquaintances, our relations have always been quite distant. Not that we have had any disputes, so, on the other hand, the relationship is the same as it was."

This behavior is not unusual: in many families there is one person who does not accept the child with a cleft, at least not at first. Sometimes this leads to a situation in which the contact is and remains broken between some members of the family and a relative or a friend. Sometimes it turns out to be a misunderstanding of some sort:

M (22): "Well, you see, we were at the maternity hospital at the same time, my brother's wife and I. She gave birth to a boy the day before. He was quite healthy, except that he was almost premature, but quite healthy. And my sister-in-law, she got this feeling that she didn't dare get in touch with me, we are terribly close, but she didn't call me. And she didn't know how to speak about this matter and how she should discuss it with me, because she felt guilt for having had a healthy baby, which hadn't even occurred to me, or that I would be bitter because she had a healthy baby. But she somehow felt guilty."

I: "Did the situation get cleared up?"

M: "Yes, I called her and asked her if that was it, that she had a bad conscience about it or something, if that was why she hasn't been in contact. And she said it was because she didn't really know what to say. Like, if she complained about the baby spitıng up, she'd feel stupid. That's when I told her not to think about it, that we also have the normal baby problems.

I think the reaction was (otherwise) good, except that I would have expected more of my own mother."

I: "Were you disappointed in some way?"

M: "Yes, it's just that I had to be her support when basically you would expect that your mother would be there for that purpose and that you could trust her and tell her everything, and that she's there to help you, and that she is, well, a mother is a mother.

And I assumed that I could have talked about the surgery for instance, I don't want to complain, but sometimes you have to talk to someone about what's on your mind, how hard it is to be here and so on. And I thought I could talk to my mother. And that was a disappointment for me, and even now when I called her from here and explained how he has caught a cold and his mouth is bleeding and it's too much for me, that she would have some sympathy, that she could at least imagine what it's like, but she just said that I have to manage."

I: "Have you otherwise been able to find this kind of empathy or sympathy?"

M: "Yes, I have, but it's terribly contradictory. Naturally you tend to underestimate it, that it's just a minor cosmetic handicap and can be operated on, and his life is not at stake and all that, you just don't want to think much about it. But then, for example, a friend of mine came to see me and said that it's quite trivial, and I got terribly angry, like how can she say that, (laughing) that it's trivial, even though I keep saying it to myself... but God forbid if someone else comes and tells me so. There are, for example, people who are jealous because I get 1000 marks a month allowance for the care of my sick child, they think I should be happy to get 1000 Fim extra money (laughing) every month, but there's got to be all kinds.

Once I got furious when I went to the shop to get baby's milk mixture, and I didn't even have --- with me, so an old lady in the check-out line started ranting at me how terrible it is that people give stuff like that to their babies, that they should be given breast, and then I turned around and said 'listen, my baby hasn't been able to take the breast even once, so shut up, he has a cleft lip and a cleft palate, and it's good that he can take this', of course it had been a bad day for me. But what made me most mad was how the hell some old bag who knows nothing about anything can come and tell me that I'm a bad mother because I give my baby a milk mixture, and that's why I blew up."

It has been more or less difficult for every mother with a child with a visible cleft to take the step out, to tell relatives and friends about the cleft, to take the baby to the grocery store, to show the baby to neighbors. They also talk about a "recording tape" that started to "talk" immediately when somebody asked something about the cleft - and even when nobody asked anything. Always the same questions, always the same answers. However, after a while, the mothers stopped talking about the cleft and only answered direct questions, and these too, in the shortest possible way.

I: "Did you think it was hard, this little word "but" you had to say, that everything has gone well, *but*... was it difficult to manage it in the beginning?"

M(30):"No, and maybe just because I didn't react to it myself. In the beginning it was not, I explained it just babble babble... but when I started it over for the hundredth time, I thought 'oh God, why should I explain this, *it's my baby,* and since it's something that can be fixed, since it's not permanent... so that's why I sometimes thought, or I was quite exhausted."

Many mothers react with exactly the same expression: *It is my child,* so why do I have to explain so much? Since the family has accepted their child as theirs, and as a member of their family, they expect other people to do so as well, and consequently they stop explaining.

I: "Was there a 'tape' that always started running?"

M: "Yes, there was."

I: "Is it still on, or has it grown fainter?"

M: "It has grown faint. I think I have accepted the matter so perfectly that I need not explain it any more."

The problem of shame, stigma, and concealing is an immense one, and can be explained with different theories. This aspect of the cleft lip and/or palate problem will be returned to in Chapter 5.

Changing Looking-glasses

M: (9): "Seen in the mirror he looked different, I wondered if he looked like that to strangers?"

Many mothers reported that after a while they could not "see" that there was anything special with the appearance of their child, but that the mirror or changing environment "opened" their eyes: when they where at home, they did not notice anything, but when they visited a department store, they noticed that their child looked different. The mother had been on a few days trip, and when she came back she got a small shock: she had forgotten how her child looked. They also found photos to be documents of something that they had forgotten.

I: "Some mothers have said that they have learned to look at the child with their own eyes, but every once in a while they looked the way other people look, or with other people's eyes, did you experience such changes of spectacles?"

M: "(38) I remember one incident. We had a roll of photographs taken of ---, and when you look at these photographs, you see it much more clearly. It's funny how they, or now that you have looked at the pictures after the surgery a year ago, now you notice that he looks different, that he looks quite different from normal babies, or different from how he looks now, but it's funny that you didn't notice it then. It's just the same, I have tried to look but I can't see anything strange in the lip, and all the time perfect strangers who come to talk to me, or distant acquaintances come and ask me what --- has got in his lip because it's like that, that it's thicker here on one side, and I don't notice it at all, but perhaps I will some time."

I: "And in the mirror, some mothers say they suddenly notice in the mirror, hey, just a moment, he looks different in the mirror?"

M: "That's true. I think in the mirror his face doesn't look symmetrical, not even his nose. I think if you look straight at him, like this, his nose looks very symmetrical, only one nostril is a little different from the other, but when you look in the mirror it looks terribly different. And it's quite true, but I have thought that the mirror somehow emphasizes such small distortions. We'll see it then, or that's what they say, that there will be some examination before he goes to school, which would be quite nice, if other people think --- looks different, maybe it would be a better start for --- at school."

And another mother:

I: "Did you feel in the beginning if you saw --- in the mirror that he looked different somehow?"

M (27):"Yes, somehow you see it more realistically that way. Actually it looks worse then."

More comments of this kind.

M (22):"There was this, now that I look at the pictures afterwards, I felt like crying, 'oh God, how can I have considered this a beautiful baby, when she looked so shocking, but now that she is different, my eyes really water, good heavens it's no wonder people stared at her because she really looked quite awful, but for me she was the most beautiful baby in the world, I never thought there was anything about it. But afterwards, looking at these pictures really made me cry, like oh my, did she really look so horrible."

I: "Were there situations when you saw her with other people's eyes?"

M: "No, only afterwards in the photographs, but not then, and that's just why my eyes filled with tears. I did see that she looked worse in the mirror, and it occurred to me how she looked different when she looked worse in the mirror."

This aspect of cleft will also be discussed more in Chapter 5.

3.1.6 The Information the Parents Received

Several studies indicate that the information the parents get has an essential impact on their capability to take care of their infant with a cleft, and on their capability to adapt to the new situation. Since there are no previous studies on this subject in Finland, this dimension of the cleft palate problem was seen as an important one.

However, the reader is asked to be alert to the fact that the questions about the information the family has received are answered from the mothers point of view: that is, she can only offer us the information that she remembers, and as she has experienced it from her personal point of view. If we would ask the midwives, nurses, and doctors at the hospital the same questions, the answers would not be the same.

The Information that the Family Got Immediately after the Delivery at the Hospital

> "It's remarkable considering that this is such a common problem, that the staff at the maternity hospitals know absolutely nothing, you get no advice or help, and thinking that a mother may cry for three days at the top of her voice, when she only has a clefted baby. But because looks are so important anyway, when you look at the pretty babies, and they take the breast and suck so well, and I have this ugly monkey, and I'm lucky if I can make him eat anything even from the bottle. And, if you're in that state, you can cry for several days, but there should be a parent who comes there with a clefted child and explains: 'now you are going to stop crying, look at my son here, there's no reason to cry.' "

Not every mother had experiences as bitter as the mother (28) above, but many of the mothers felt that they did not receive enough or adequate information.

The mother was a nurse herself, but that did not help much when she got her second child, a girl with a cleft lip and palate (29):

M: "It really was a shock, I didn't realize it, I think I denied it, I put it aside. And in Salo there is a midwife who has a daughter in her twenties who has had a cleft palate, so she came on the first day to explain this thing and she brought the booklet, but I don't remember anything she said. I just remember her there beside the window, and I remember nothing about her story."

I: "The social worker didn't come to see you automatically?"

M: "No. I asked for her number and then I went to see her. She was active in the sense that a baby like this had been born in that hospital six months earlier. so she had a leaflet with all the social information, so I got some information there. But then, for instance, the pediatrician had said that the first surgery would be at two months, and I waited and waited but nothing happened, and then I thought they have skipped us and I called here (Cleft Palate Center) and heard that because she has a partial (cleft) only, it will not be until six months. In this sense, information just about things like this, that when the cleft is partial, it only needs to be operated once, and no one knew that, no information whatsoever. And it makes me wonder, when the persons in question are pediatricians and ear specialists who should have some idea about it, and nothing. And then when I got the information here, then I was the informing party."

I: "Do you think you should have gotten it (the information) already at the maternity hospital?"

M: "Something, because the information at the maternity hospital was really meagre. Like this thing about the nipples and the long nipples (cleft nipples), they knew nothing at the hospital, and I got this feeling that I should just pump and pump, and try with all kinds of nipples, but no one had the enthusiasm and interest to make sure the baby was correctly fed, so I just had to feed her and it took very long."

Another mother (25):

M: "It was really a hit or miss thing, the whole business at the hospital. They actually knew nothing about the cleft. I had to dig out everything myself, what this is all about."

One thing is to get no information at all. Another thing is to get wrong information, which can be fatal.

M: "They gave me a booklet with all the possible information you can get if there is something wrong with the baby. And then at the maternity hospital there was a phoniatrician who told me to avoid certain sounds in front of the baby, and then I asked about it here (Cleft Palate Center), and they said how can anyone say that, and how can you start selecting what you say when you talk to the baby. I don't remember what the sounds were I wasn't supposed to say, but some pa-pa-pa and ta-ta-ta or something I was supposed to say and something I wasn't. So they actually gave me wrong information."

The mother (20) of a girl with a cleft palate (her third child) was told to breast-feed the baby in an exotic manner:

M: "The pediatrician told me to keep the baby's head up (when I nurse her), but it wasn't more than half an hour when the feeding time came and an elderly children's nurse brought --- for her feed, and it didn't work at all... and then she became uneasy and then she was hungry. And she was very determined, the nurse, and she said that all mothers can nurse a baby, period, that all mothers can. It didn't strike her that all babies cannot suck, especially when they have a structural malformation like this, and it was really miserable... and it made me cry, though I consider myself a pretty balanced and strong person... And the children's nurse turns the toes like this (pointing up in the air), like the other way around. She had the impression that some babies get a better hold of the breast when they are upside down.

Usually when I breast-feed, and I have fed others like that, the toes are where mine are too, and when I lay there, as I had been operated, I tried it so that she was under my arm with her head a little up, like I had fed the others too, so this (nurse said) we'll try this system once more, that some babies get a better hold if they are like this, and she held her with her head down. And I said good heavens, no, the doctor just gave me instructions that

> the head must be held up, so it (the milk) won't go in the nose, but no, we'll try like this, it's all right... and she took --- by the neck like this, some older ones are really rough, she grabbed her here and said that you can suck. And it was real tough in addition to all the worry and depression and everything there is with a baby, then you have to fight with the staff there. I don't know if they simply lacked the knowledge, I don't think they do it out of malice, I think they don't have the knowledge. Now I can talk about it calmly, but then there really was a quarrel, after I was mentally recovered, there really was some argument about it."

One need not be an expert to understand that a child with a cleft cannot eat upside-down (if any child can). Fortunately enough, the mother had been breastfeeding babies before, and was strong enough to resist the attempts of the nurse. However, to feed a baby upside-down is not as hazardous as it can be to insist on feeding the baby through a tube:

M: (34)"--- (a baby with a bilateral cleft lip and palate) was really very lively and very zippy, a very energetic baby and she had a very strong sucking reflex, and they put on the feeding-tube automatically. And I insisted on trying to feed her normally, but no, and not really, and no and no... Not one single cleft nipple in the whole hospital. And then I fed her with normal nipples, but nothing came out because it was so small, the hole (in the nipple), and I asked them if I could make it bigger, so she (the nurse) said absolutely not, she will choke...

> And we talked real seriously... and I thought the baby will have the tube until she is one year old, that she can't be fed otherwise... --- had the tube all the time... and after we were discharged, she half pulled the tube out herself , and then my husband completed it and wrenched it right off (laughing). In a couple of days we got her eating quite properly without any tubes."

> But when they visited the hospital a week later, the tube was replaced:

M: "The nurses were very angry with us and they said we have to come to the hospital immediately if the tube comes off, and I tried to explain that --- had been eating very well... but they didn't believe our story...We were terribly happy and glad for having made such a good start on this (feeding) when we went there, and they turned us down completely and gave us very nasty feedback."

I: "What did you do then?"

M: "We went back home and my husband pulled the tube off at once and we fed the baby quite normally."

A week later they visited the hospital again, and now they knew that the weight gain had been good:

M: "This chirpy lady (the nurse) said 'well...it has increased enough'... We had brought some food for --- with us, and we started feeding her, so people gathered, there were eight people who had some business or other passing by and they peeked at us, and --- ate perfectly, and after that we heard nothing about it from them... but I think this matter could have been dealt with in some other way... or at least so that they wouldn't give people wrong information if they don't know."

These parents, and especially the father, were strong enough to resist the staff at the hospital. But in some cases (not included in this study) the parents have not been so strong, and the baby has been fed through a tube for up to 9 months or a year.

The Advice Bureau for Postnatal Care

In Finland we have a well-developed system of maternity welfare with both antenatal and postnatal care. The advice bureau for postnatal care provides information for parents about the child's health, about feeding the baby and about educational issues. At the beginning, the mother or the father brings the baby to the advice bureau every week or every second week, then once a month and later, after the child's first birthday, once a year until the child is of school age.

The parents have expectations of getting advice and information on every aspect of the child's health, and in consequence, if they do not get advice, they feel disappointed. Since there are several hundreds of advice bureaus in Finland, one cannot expect to get a clear picture through this study of the knowledge they have at the advice bureaus about the cleft palate problem. On the other hand, there is no reason to believe that the advice bureaus in this study are all exceptional.

I. "Did you get any information anywhere else? What did they tell you at the advice bureau?"

M (37): "They know nothing at the advice bureau. A very nice nurse, but since she had no experience, she just didn't know, and she actually asked more of me, like 'what have they told you about this?', and 'when do they do that?', so the advice bureau had no information whatsoever. If you think where you could have gotten some information, I think if they had given me a booklet at the maternity hospital with all the possible information, I probably wouldn't have wondered at the advice bureau whether there was any sense in distributing the information to all the bureaus. The scales here are much bigger than in the hospitals where the mothers are, and there it goes directly to the right target. No one is interested in this except the people who have a (clefted) child of their own... she (the nurse) said she had heard such and such from a colleague. But when it's only hearsay, it's not exact information, so on the contrary she asked more of me, and the advice bureau couldn't give me support."

This mother had the feeling that nobody was interested, unless they had a child of their own with a cleft. The next mother is a doctor herself, which she found only made things more difficult for her:

I: "How was it at the advice bureau and other places you have visited?"

M(36):"At one time when --- had had otitis and a urinary tract infection and this cleft, the doctor at the advice bureau asked me how we have been, and I said quite well, that he has otherwise been a healthy child except for these. So he (the doctor) said 'yes, there was also a mother of a baby with Down syndrome who said that it's a healthy boy, he just has Down syndrome... So it seems people are still terribly prejudiced, even professional people. I heard the most awful comments from the doctor at the advice bureau and the pediatrician. It surely wouldn't give you much comfort if you heard something like that from an advice bureau doctor. I don't know if I also get, or if they overreact, because they think I'm a colleague, and they forget I'm the child's mother. I think that's the biggest mistake in the attitude of the health-care personnel. They assume that I'm perfectly objective, and I think that's why I have heard these comments, but they are a little shocking. After I heard them I thought, damn! Well, I then got sinusitis myself, and when I went to the hospital or the health center, and they asked me my occupation, I said I was a housewife."

Another mother of a boy with a bilateral cleft lip and palate:

I: "How did they react at the advice bureau?"

M: "(27) When we went to the advice bureau, the nurses and the other people there, they pitied me so terribly and they said, and this made me feel a little miserable, they said what's unfortunate with these cases is that they suffer from all kinds of infections. And even though you know it may be true, it makes you feel quite depressed. I have realized, and especially afterwards, that in a situation like that nothing is more important than having someone who would tell me every now and then that everything can go quite well, that it's not necessarily so bad, and --- didn't have so much of that and he hasn't been so terribly ill.

Then also one nurse, when we went there for the first time, she said that *these babies usually have other disabilities as well,* and have we noticed something else out of the ordinary, about the ears or something, and then I thought how awful."

I: "Did she really say there's usually something else?"

M: "Yes, and then she said that there had been a little boy who had also had this and then they had noticed at the advice bureau that there was something special about his ears, he had exceptionally large earflaps or something like that."

I: "It must have scared you?"

M: "Yes I did get the feeling that I have to prepare myself, that anything could still be found, and it felt bad."

Another mother got the same, and wrong, information that children with a cleft palate usually have additional problems:

I: "How did they react at the advice bureau?"

M (19): "They couldn't give me any advice. They just said that I should do as I feel best. They know nothing about clefted children, and it felt a bit strange when I asked them for advice, what I should do and all that, they just said I have to see for myself what's best.
And I asked them about the breast pump I had in the beginning, whether it's their duty to get one for me because I have a clefted child, but they didn't, and I had to get it myself, and I think that's wrong anyway; the advice should come from them."

I: "Was the advice bureau particularly worried, did you go to weight control more often?"

M: "No. I have gone quite normally, as I told them that I would not bring him there every week. The only thing I was afraid of in the beginning was that he would not develop or his weight wouldn't increase, *since it is normally the case that clefted children don't develop* and this is what they told me at the advice bureau and I thought it was kind of... and that's when I started following it myself and did everything I could to create some progress."

I: "So you followed very carefully whether he smiled or turned his head and so on?"

M: "Yes, I wrote everything down. I have followed him really carefully and what I'm proud of is that --- has done almost everything in the potty since he was 3 months, he doesn't dirty his pants much (laughing) and I think it's something, usually that happens around 9 - 10 months, that they learn to use the potty. We have had very many days when I put him on the potty after breakfast and he does both things in the potty, and then the same again after lunch and after dinner, and it comes quite regularly if only I take the time and the trouble. I have noticed that --- has developed enormously, he already draws on paper, now that he's twelve months. The development has been very good at least so far (laughing)."

I: "But at the advice bureau they had this outdated idea, that they (these children) don't necessarily develop?"

M: "Yes. But I wouldn't think much of it if I had another one like this, really it's just, if there's nothing else besides this (cleft) it's so little."

This mother was really concerned about the development of her child, and had made an immense effort to prove to herself and to the nurses that her child was normally developed.

But there were also positive experiences:

M(13):"On the next weekday I called the advice bureau and asked if they could do feed weighing. You see we have a lovely little advice bureau with a wonderful staff, and I could call them about things like this. And they said 'of course, you can come every day if you like'... And then when --- was about 6 months it happened that they got a substitute and she had also had one (a clefted child). She is now 3-4 years, this girl with a cleft, and all my appointments were extensive because she liked to tell me things. And I told her, and then I said this is what I have been waiting for, to have someone with the same problem to talk to, and it did an awful lot. And when we were on our way out she had managed to weigh and measure the baby on the side, so she wrote her home number on our health information card and said that I could call her if there was anything. And I tell you, knowing that there's someone I can call has done a lot."

And again a mother with the same experience:

I: "How did they react at the advice bureau, did they have information, did they know what to say?"

M (39): "Well, I don't know, at least they had nothing new to tell me. But it was quite funny last autumn, before my maternity leave ended. You see, the nurses changed all the time, when one left for maternity leave and then the next one, but what I thought was nice when the one (who substituted her) had a cleft herself and she was pregnant, so she was very interested. And she said all kinds of things about ---, how well she was and how small it (the cleft) was and then she told me what hers had been like, and I thought it was quite nice."

I: "You had a nurse who had a cleft?"

M: "Yes, and who was going to have a baby."

In summary, the information that the mothers had received from the postnatal care system depended on the personal interest and activity of the staff at the advice bureau. But the mothers felt that the most important link in this system was the information they received at the hospital immediately after the delivery - and this information should be as positive as possible. Many mothers also complained that they were considered to be experts, and they were asked questions: they were considered the giving part in a system where they would have preferred to be the receiving part.

3.1.7 Development of Self

Some of the mothers spontaneously said that this event had changed them as persons. In this study some of the mothers expressed that they were willing to help other families in the future:

M (13): It came up here at some stage that in some hospitals there is a list of parents whom you can contact if you have a handicapped baby, who have had one themselves, and it has occurred to me that if someone (a parent) like this wishes to contact me, they could do it, I would like to be of assistance to somebody that way."

Many of the mothers also described some change in their way of being.

I: "Do you have the feeling that you have yourself developed in some way?"

M(2): "Yes I think so. I suppose I wasn't able to listen to others before, or if I did I didn't know how to respond, and also because I always was a sensitive person and especially now after --- was born, I somehow feel that I could have said a word of comfort to such and such then, and I notice that many things move me. And I make phone calls to people and I feel it in my heart that I have to call them and cheer them up and help them, I do think something has happened, that in me some stones have been broken and flesh has come in their place."

M(25): "Yes I think this has changed my own outlook a lot, on all values of life, and they have all changed enormously, things that were important before are not important any longer."

I: "Could you give an example?"

M: "Let's say for instance some, let's say a new spring outfit, it doesn't feel as important as before. Or something else, let's say a holiday trip and things like that, we have dropped them altogether , and we haven't even wanted to go anywhere. We have had no interest, and, say, three years ago we would have gone shouting with joy, and we would have been terribly disappointed if we couldn't have gone."

I: "And you and your husband, do you stick together ?"

M: "Yes, we haven't in that sense, it has only strengthened our relationship. It has apparently been a unifying factor for the whole family; we stick together even more firmly than before. Neither one of us wants, for instance, if I'm on a business trip I drive home if it's less than 150 km away, and then back the next day, and I may do that three days in a row, and it doesn't feel hard at all, but before I would of course have stayed the night, I would on no account have come home, I couldn't drive home 100 km, and now I don't even consider not coming home for the night. And I think this has changed me only for the better."

Some mothers felt that if these things have to happen, it is good that it happened to us, because we have the capacity to deal with this:

M(17): ...so finally I have thought that it was good it happened to me, that it didn't happen to someone else, and I think I'm able to deal with it sensibly."

But a couple of mothers also protested against this: yes, they had changed, and yes, it was a positive change, but was it necessary? People grow as persons even without any major crisis.

M (10): "I didn't want this development, I would have been good enough as I was, I would have been good enough as a less good person...but the development hasn't been negative anyway."

The mother who lost her first baby in SIDS, while her second child had a cleft lip expressed her feelings in this way:

M (38): "I have been wondering about it, I have wondered what's the point. For example, there has been this phenomenon which I think is quite natural, that I had lost all faith in all the higher powers and spirits and I'm now a perfect atheist. I had been oriented that way before, I had been terribly anti-Church, but I nevertheless believed that there is a higher power, but I don't believe in that anymore. I have become quite cynical in other ways too, which is natural."

I: "Have you tried to find a meaning for what's happened to you, or to create some meaning for it?"

M: "I don't think there is, I haven't really found anything to explain what the meaning could be. I think people grow and mature even without any great hardships. Indeed, if they had a meaning, then it would be somehow predestined, and I don't believe in that. Or if I did believe (in God) he would have to be quite incredible... or I think he would be a real lousy guy (laughing). But I really don't believe in anything like that. I think it is, or what happened to us for instance, it's only a coincidence, I think it's pure coincidence. Of course there may be some things that have had an effect, which we haven't considered, but nothing that we could do anything about."

I: "You have obviously got the situation under control, as you are a founding member of a SIDS association, and you intend to do something in this field in the future?"

M: "Yes I have, and one somehow gets, let's say it's such a terrible fright, such a terrible incident, that if one doesn't try to get a hold of it at all, anything could happen. One could slip into quite different depths for the rest of one's life. And indeed many mothers have gone to all kinds of therapies after incidents like this, or they have been deeply depressed or something like that. I think the only way to get a hold of it is to do something, and especially in the beginning it was quite clear that I wanted to do as much about it as I could. Now I'm more relaxed about it, it has become more a part of my life. You can easily see that with parents who have recently lost a baby in SIDS; so many parents go through this phase when they want to do something about it; they all want to participate in research and they want to know what it is, and they are ready to do any amount of voluntary work. And I have noticed that it's a transition period, and then there comes a time when they are no longer so interested in this work, they are more interested in thinking it over by themselves."

I: "You think that these are phases people go through, sort of phases of mourning?"

M: "Yes, phases of mourning."

I: "That you cannot remain passive and only accept what fate has in store for you, but try to be active?"

M: "I think you must, and for me at least it's the only alternative, and I can see it is for many others too, because I think if you only receive, it can break you down, it would be a sledge-hammer that just comes out of nowhere and if you don't do anything, if you don't protect yourself, it can in my opinion break a person down quite completely."

Discussion

The main purpose of this chapter was to describe the diversity of the experiences that the mothers had and to describe the problems they had to face during the first year with the new family member. Since it is impossible to describe all the experiences and all the topics, the selection was made according to the special interests of this study: to find possibilities for intervention. Some other topics and the answers to them are listed in the Appendix.

The material is organized under certain topics with no theoretical explanations Therefore, some of the topics will be returned to and probed in the next two Chapters. However, a descriptive presentation of the material gives the reader the opportunity to come to his own conclusions about the material. This descriptive stage has also the function of making some of the feelings of the mothers explicit, which makes identification possible for others in the same situation. To be concluded from this chapter: there can be little doubt of the existence of a psychosocial aspect of the cleft palate problem.

4. INVARIANT FEATURES: FINDING REPEATED PATTERNS.

The fourth rule of the phenomenlological method and the essence of eidetic reduction is: Seek the structural or invariant features of the phenomena. That means that repeated patterns are significant and must be probed (Ihde 1986, 39). This stage is the positive part of epoché, *the reduction to.*

We are now moving the focus from an immanent level of personal experiences and personal interpretations to a inter-subjective level of experiences-in-common. Repeated patterns are significant and help us to find the essence of becoming the mother of a child with a cleft. Repeated patterns also help us to find possibilities for intervention strategies, to answer questions of when, what, and whom in order to develop education programs for these families.

In this chapter we focus on the essence of cleft; in the next chapter the focus will be on existence. The method here is to look at frequences according to specific interview topics and to test repeated patterns by using nonparametric statistics applicable for small samples, when the level of measurement (scale) is nominal (Siegel 1956).

4.1 Maternal Responses to Specific Interview Topics

In order to examine closer claims number 1, 5 and 6, and in order to discuss claims number 4 and 7 derived from different theories in Chapter 2 (see page 62 - 64 for a summary), topics according to a) the mothers' feelings during the baby's birth or when she learned about the cleft, b) mothers' expressions of early bonding, c) eating and feeding difficulties, d) mothers' explanations of their acceptance of the problem, e) mothers' descriptions of the weight gain of their baby, f) mothers' experiences of separation, and g) mothers' descriptions of emotions during the first year. The information the mother received at the hospital will also be listed.

The answers were listed in a data matrix (see the Appendix). The next tables (Table 6 - 17) and crosstab tables (Crosstab table 1 - 15) are all based upon the matrix. The numbers after each comment in the tables refer to the mothers. The focus here is on maternal - infant bonding, since in an educational context this process is of vital interest, when the ultimate goal of parental education is to have a benefical impact on the children and to assist in their growth and development. Therefore, there will be an attempt in this chapter to study the impact of cleft type and feeding difficulties on the early bonding process.

Feelings at the Child's Birth or when Learning About the Cleft

According to the attachment theory (Bowlby 1988), an infant's attachment to the mother develops during the first year of life. The maternal-infant bonding process begins at birth, if not before (Klaus & Kennel 1976). Ainsworth and her colleagues strongly suggest that the quality of maternal-infant bonding is a strong casual factor in the quality of developing attachment relationships: throughout a child's lifetime the strength and character of this original mother-infant bond will influence the quality of all future bonds to other individuals (Bretherton, Biringen & Ridgeway 1991, 1). A question of the mother's feelings at the child's birth or when learning to know about the cleft is then highly relevant. It is important to note that a classification of feelings as "positive" or "negative" in a moral sense is avoided here; it is equally "right" to feel sad or happy when the baby is born.

As we can see from Table 6, the descriptions of the feelings at the infant´s birth varied a lot. Only two mothers mentioned that they were pleased with the baby' s gender, and both of them also mentioned that they did not quite understand when the doctor talked about the cleft. None of the mothers described pure happiness, but one mother mentioned the cleft (cleft palate only, and her third child) as a small black spot in a big, happy cloud. One mother described her feelings as pleased at the moment and that she started to cry later, one mother felt that she cried because it was so wonderful to have a baby and that she did not quite understand what the doctor told her about the cleft.

TABLE 6.

Feelings at the Child's Birth or when Learned About the Cleft

1. It was a shock 7,12,14,20,21,24,28,29,32,34	10
2. It frightened me 1,6,10,17,18,31,36,37,40	9
3. I did not understand 12,8,10,11,15,29,22,29	9
4. It confirmed my suspicions that something was wrong 1,2,5,6,8,9,31,32	8
5. I cried 2,9,20,22,28,33	6
6. Felt sorry for the child 2,9,25,39	4
7. Felt relieved that it was not anything worse 12,13,17,38	4
8. It can't be true, I will soon wake up 7,24,28	3
9. I did not feel anything 26,30,35	3
10. What else will it have 14,31,36	3
11. It does not matter 27,30,38	3
12. It was a disappointment 3,16,17	3
13. I do not remember what I felt 8,21	2
14. I was afraid that the child would die 19,34	2
15. Pleased with baby's gender 15,29	2
16. I have failed 11,16	2
17. I said that I didn't want this child 23	1
18. Is it my fault? 24	1
19. I was not shocked, because I knew that it could be fixed 27	1
20. I was pleased at that moment 5	1
21. Disappointed with baby's gender 26	1
22. I was in a big happy cloud with a small black spot 13	1
23. I thought about what other people would think 4	1
24. We have got a baby, how wonderful it is 22	1

Note: Figures refer to the number of mothers who gave a response in each category. They could give more than one response, but every mother gave some response. Hence totals do not add up to 40.

A total of four mothers expressed that they did not feel anything, or felt that it was not a shock, because it could be fixed, or that it did not matter. Compared with the feelings of intense happiness that have been reported among mothers of healthy new-borns (Bretherton, Biringen & Ridgeway 1991,10) (which, of course, is not always the case even when the child is healthy), the description of a lack of feelings is striking. However, these five mothers did not describe themselves as shocked or frightened.

Two of the mothers who did not describe any negative feelings had had a child with a small incomplete cleft lip. One of the mothers had a previous experience of the death of her first child (in Sudden Infant Death Syndrome, SIDS), and she compared this experience with that: *"Earlier experiences brings the cleft lip into a context where it cannot be considered as the worst thing in the world"*. The other mother had two children before, and compared this delivery with previous deliveries: "*I have really thought about why I didn't react any stronger, but when it was exactly as it was with the others, you know. That I could breast-feed her and she didn't have any problems with anything, so it must be the reason why I wasn't more shocked than I was*".

The third mother had a girl with a very small cleft palate only, her second child. She also reported that she breast-fed her baby. The fourth mother had a child with a bilateral cleft lip and palate. Her husband had a cleft lip, and she knew immediately that this was something that could be fixed: "*In the beginning I was even too optimistic about it, I didn't realize that when there is a cleft in the palate, it is a bigger thing*".

In summary, only 4 mothers did not describe themselves as shocked or frightened in any way, but they did not describe any feelings of happiness or satisfaction either. Four mothers described both feelings of happiness or satisfaction and other feelings, and 32 mothers described themselves as shocked, frightened or sad. The point here is maybe not so much what the mothers said, but what they did not say; maybe not so much what they felt, but what they did not feel. The repeated pattern here can be described with the words of one mother about what she felt that was missing: "*The happiness after the delivery*".

This seems to be an experience-in-common for all the mothers that is not related to the personality of the mother, to her previous experiences, or to the cleft type. It is interesting to note that even if the news about the cleft came later (as might be the fact when the baby had a cleft palate only), there are no descriptions of the feelings of happiness at the child's birth. Usually the mothers said that they were suspicious about some different sounds the baby had made (cried differently, could not suck) or that they noted that milk or water came out of the baby's nose. Another explanation for this is that when they finally learned about the cleft, their feelings were overwhelming and erased the feelings they might originally have had.

Mothers' Descriptions of Early Bonding

When the mothers describe the bonding process, they differ quite a lot from each other. Nine mothers out of 40 (Table 7) say that they love the child more because of the cleft, and some also think that every mother must do so. If they have more than one child, they have a bad conscience about loving the child with the cleft more than its sibling(s). Eight other mothers used the world "love" when describing their feelings, and one mother looked at me and said: *"and I'm not saying this only because, you know, one should, I really do love him very much".*

TABLE 7.

Mothers' Descriptions of Early Bonding

1. +I love the baby 36, 11,10,2,39,30,33	7
2. +I love this child more than its sibling(s) 29,14,13,21,34	5
3. +I love this child more because of the cleft 25,19,1,27§	4
4. +I have been thinking about my child as a healthy child 15,18,35,37	4
5. -I hesitated to take care of the child at the beginning 33, 31,16	3
6. -Husband was closer 36, 23,16	3
7. -It took a long time before I could attach to the child 23,16,32	3
8. +I am proud of my child 22,8,37	3
9. oMother does not talk about bonding issues 4, 20, 28	3
10. -I had difficulties to understand the child 1,17, 7	3
11. +It's very difficult for me to leave the child 6,11	2
12. +I would not have changed the baby (for another) 9	1
13. +When I took her in my arms, I forgot everything, she was so sweet 2	1
14. +I am more care-giving, but that's the way it should be 33	1
15. -I hated her in the beginning 16	1
16. +I love all my children equally 3	1
17. +The baby was wonderful despite the cleft 24	1
18. +We had planned for this child, no problems 12	1
19. -The child was not planned for, it was terribly difficult at the beginning 7	1
20. -I did not take enough notice of the baby 18	1
21. -The child is clinging, which I think is heavy 5	1
22. -I don't have the time and energy to carry the child all the time 17	1
23. +I got used to it very soon after the birth 26	1
24. +The child is so sweet, I take him immediately into my arms if he cries 40	1
25. - I thought I'm going to kill this baby 10	1

Note: Figures refer to the number of mothers who gave a response in each category. They could give more than one response. Hence totals do not add up to 40.

It is important to note that they were never asked "Do you love your child?" (which would have lead to very homogeneous answers), so the mothers are describing their feelings spontaneously.

Then we have a group of 5 mothers who describe the early bonding process as very difficult. They have feelings of rejection, they do not want the child, they do not want to take care of the child. Two of these mothers say that the father was closer to the child at the beginning.

All in all, 17 mothers use the word "love" and a total of 25 mothers express no difficulties with the early bonding process, 7 (5, 7,16, 23, 31, 32,17) mothers describe only feelings of rejection and 5 (1, 10, 18, 33, 36) mothers describe both bonding difficulties and their success in bonding. Three (4, 20, 28) mothers are difficult to classify: They do not talk about bonding issues at all. Note that descriptions number 5, 6, 7, 8, 17, 18, 19, 21, and 24 are descriptions that are classified as expressing rejective feelings. This may be criticized, for example descriptions number 19 and 21 are descriptions that belong to the everyday life of the mother of a small child. These expressions must, however, be seen in the context in which they appear, which cannot always be fully explained to the reader. This context is taken into account when making classifications of the mothers. Hence, it is not possible to make the classification criteria fully explicit, but for the most part they are.

But there is one more thing that should be taken into account. When studying the material, I found that even if the cleft did not create direct problems for bonding, such as rejection of the child, the situation might have been very difficult as a whole, and thus indirectly influenced the possibility to create a good relationship with the child. This might be the case when the mother is very exhausted and does not receive any help to handle the situation, or when the mother is very depressed and thus potentially not so responsive. Depression in parents is likely to increase psychological unavailability, and in prospective studies of parent-child attachment psychological unavailability has been linked with insecure attachment (Cummins 1990, 348).

Since one of the major problems when a child is born with a cleft is the problem of feeding, it is natural to examine how many of the mothers reported such problems.

TABLE 8a.

Mothers' Descriptions of the Feeding Situation, Liquid

1.	Extracting breast milk with a pump for some time 1,2,3,5,6,8,10,11,12,14,15,16, 17,19,20,22,24,25,27,28,29,31,33,34	24
2.	Difficult at the beginning (the baby eats very often or feeding takes a long time) 27, 25, 34, 32,19,17,11,12,7,18,1,9,22,3 ,24,31,20,9,5,8, 23,15,	22
3.	Disapointment that I could not breast-feed the baby 31,17,14,11,12,5,3,20,29,4,6,23,34	13
4.	The feeding suceeded well with a nipple with a big hole 23, 36, 27,29, 33, 32,20,15,4,14,8,6,5,	13
5.	Giving milk mixture from the beginning 4,7,9,18,23,26,32,36	8
6.	Breastfeeding 40, 35, 38,13,39,30,37,21	8
7.	I was proud of giving the baby breast milk, despite the fact that I was not able to breast-feed it 1,2,6,12,15,25	6
8.	A lot of difficulties 28,16,10,2,26	5
9.	No particular problems 6, 14, 29, 33,36	5
10.	Tube-feeding at the beginning 34, 31,17,2	4

Note: Figures refer to the number of mothers who gave a response in each category. They could give more than one response, but every mother gave some response. Hence totals do not add up to 40.

TABLE 8b.

Mothers' Descriptions of the Feeding Situation, Solid Food

1.	Difficulties at the beginning 24, 27, 29, 32, 31,20,18,6,3,1,13,5	12
2.	No particular problems 36,17,15,40,38,39,30,21,4	9
3.	No description 25, 23, 34,16,14,11,35,37,33	9
4.	Not very much trouble 10, 8 (easier than liquid),7,9,22	5
5.	A lot of difficlulties 28,19,2,12,26	5
	Total	*40*

Mothers' Descriptions of Feeding

In a study by Tuula Tamminen (1990), 100% of first-time mothers in Finland (n=279) expressed during pregnancy that they planned to breast-feed their babies. The majority of the mothers regarded breast-feeding as important or highly important for the mother-child relationship. In the study the mothers also believed that other mothers had more positive attitudes towards breast-feeding. This reflects the strong social pressure that is attached to breast-feeding in Finland. The problems the mothers in this study had with adjusting themselves to the fact that breast-feeding was impossible must therefore be interpreted in this light. (Tamminen 1990, 102-104.)

When examining the table, we can see that 8 mothers of 40 breast-fed their babies for some time and the rest (32) bottle-fed their babies. Twenty-four of the mothers that were not breast-feeding their babies, gave breast milk to their babies by extracting it with a breast pump (for between 1 to 8 months). Eight mothers either decided not to give breast milk to their babies, or did not succed in.extracting it with a breast pump. A total of 27 mothers had difficulties with feeding the baby, 5 of which had a lot of difficulties. Of the mothers who bottle-fed their babies, 5 mothers expressed no particular difficulties. Thirteen (out of 32) of the mothers expressed disapointment because they were not able to breast-feed their babies. It is remarkable to note that 4 out of 5 mothers in this study gave breast milk to their babies (either by extracting it with a breast pump or by breast-feeding) - this also tells something about the social pressure attached to breast-feeding. In Crosstab Table 1 we can see the relation between cleft type and feeding technique:

	Cleft type			
Feeding technique	CPO	CLF	CL	Total
Breast	2	0	6	**8**
Breast pump	12	11	1	**24**
Surrogate	2	5	1	**8**
Total	**16**	**16**	**8**	**40**

Crosstab Table 1. Relation between cleft type and feeding technique. n = 40

Seventeen mothers expressed difficulties with solid food and 5 more mothers expressed that they had some, but not very much trouble. However, these numbers fail to describe the amount of stress felt by the mother caused by the very fact that you are fighting with your baby every single time when the baby is supposed to eat. The problem with eating is a serious one, and might also affect the quality of both attachment and bonding. However, the mothers struggled very hard not to be angry with their babies or not to show their frustration when they finally became frustrated: *"sometimes when he started to scream (when eating) I had to go to the toilet and count to ten"*.

When crosstabulating Table 7 with birth-order, we can study claim number 1: it is more difficult for the parents to adapt to the situation if the defected child is their first child. In Crosstab Table 2 we can see that the birth-order does not divide the children into two clearly different groups (about 72% of first-time mothers and about 60% of second-time mothers express only positive bonding to the child).

	Birth-order		
Expression of early bonding	First	Not first	**Total**
Only positive expressions	8	17	**25**
Both positive and negative expr.	0	5	**5**
Only negative expressions	3	4	**7**
No expressions	0	3	**3**
Total	**11**	**29**	**40**

Crosstab Table 2. Relation between birth-order and expressions of early bonding. n = 40

However, nine of the second- (or more) time mothers said that they love this child more than his siblings, or more because of the cleft. The mothers also offered some explanations for why they could accept this problem (seeTable 9), and here we also find the explanation that the problem is easier to accept when the child is not the first one:

TABLE 9.

Mothers' Explanations of Their Acceptance

Easier to accept because:	- not a big problem,it can be fixed 2,8,9,13,18,19 25,28,32,36,40,6,29,38,12	15
	- I decided that the child is healthy 14,15,35,37	4
	- not first child 28, 33,20,6	4
	- not visible 1, 3,17	3
	- a boy 23,33,3	3
	- I decided that the child is smarter than other children	2
	- no problem, since I could breast-feed the baby 30	1
	Total	32

In Table 9 we can note that the most common explanation the mothers gave for their own capability to accept the problem was that the cleft problem can be "fixed" - which is worth keeping in mind when giving the initial information about the cleft palate problem to the parents.

When studying the relation between the sex of the child and bonding difficulties (Crosstab Table 3), among the group of mothers who express no difficulties to bond, there are proportionally more girls than boys, despite the fact that 3 mothers expressed that the cleft is easier to accept because the baby with the cleft is a boy.

Expressions of early bonding	***Sex*** Boy	 Girl	**Total**
Only positive expressions	12	13	**25**
Both positive and negative expr.	4	1	**5**
Only negative expressions	6	1	**7**
No expressions	2	1	**3**
Total	**24**	**16**	**40**

Crosstab Table 3. Relation between sex and expressions of early bonding. n = 40

Claim number 5 was extracted from etologically-oriented bonding theories, and stated the following: Early maternal-infant bonding might be disturbed if the child has a visible malformation. In Crosstab Table 4, the relation between expressions of early bonding and cleft type is studied. We can see that one group is different from the other two groups: the CL - group (cleft lip only). This result is contradictory to claim 5 and to the pre-theoretical and widely accepted assumption that a cleft that is not visual is easier to accept than a visual cleft.

Expressions of early bonding	***Cleft type*** CPO	 CLP	 CL	Total
Only positive expressions	10	8	7	**25**
Both positive and negative expr.	2	2	1	**5**
Only negative expressions	2	5	0	**7**
No expressions	2	1	0	**3**
Total	**16**	**16**	**8**	40

Crosstab Table 4. Relation between cleft type and expressions of early bonding. n = 40

A non-parametric measure of significance would be the chi-square. However, the $\chi 2$ test requires that expected frequencies in each cell should not be too small (no cell should have an expected frequency of less than 1, and fewer than 20 per cent of the cells should have an expected frequency of less than 5). If this requirement is violated, the results of the test are meaningless. (Siegel 1956, 178.)

Since these requirements were not met by the data, some categories (both negative and positive expressions, only negative expressions and no expressions) were combined in order to increase the expected frequency in the cells (Crosstab Table 5.)

	Cleft type			
Expressions of early bonding	CPO	CLP	CL	**Total**
Only positive expressions	10	8	7	**25**
Negative expressions	6	8	1	**15**
Total	**16**	**16**	**8**	**40**

Crosstab Table 5. Relation between cleft type and expressions of early bonding, combined categories. n = 40

$\chi 2$ is 1.8 (with Yates' correction), which is a non-significant result when df = 2: the observed frequencies in each category do not differ enough from the expected frequencies based on the null hypothesis.

The next thing to study is the impact of feeding difficulties on bonding. Here we can find the following:

First: *among the group of 8 mothers (2 CPO and 6 CL) who breast-fed their babies, no-one expressed difficulties to bond.* (Crosstab Table 6 and 7)

Second: *among the group of 7 mothers who expressed only rejective feelings towards their babies, every mother had a previous history of either some or a lot of feeding difficulties (liquid).* (Crosstab Table 12)

	Feeding technique			
Expressions of early bonding	Breast	Breast pump	Surrogate	**Total**
Only positive expressions	8	15	2	**25**
Both positive and negative expr.	0	3	2	**5**
Only negative expressions	0	4	3	**7**
No expressions	0	2	1	**3**
Total	**8**	**24**	**8**	**40**

Crosstab Table 6. Relation between feeding technique and expressions of early bonding. n = 40

	Feeding technique		
Expressions of early bonding	Breast	Breast pump or surrogate	**Total**
Only positive expressions	8	17	**25**
Negative expressions	0	15	**15**
Total	**8**	**32**	**40**

Crosstab Table 7. Relation between feeding technique and expressions of early bonding, combined categories. n = 40

By combining categories (Crosstab Table 7), the Fisher exact probability test was used in order to determine wether the two groups differ in the proportion with which they fall into the two classifications. We determine that for Crosstab Table 7 the probability for such a distribution of frequencies under Ho is p=0.014, which permits us to reject Ho.

These results have to be interpreted with caution. First of all, no causal relationships are found. In other words: to breast-feed a baby is no guarantee for a good early bonding. And vice-versa: to bottle-feed a baby will not create problems with bonding per se - after all 15 of the mothers who bottle-fed their babies expressed no difficulties to bond. Furthermore, this should not lead to the conclusion that the mothers of children with a cleft should be encourage to breast-feed their babies. This result might instead reflect the strong social pressure to breast-feed a baby. It might also reflect the fact that since already during pregnancy, the mothers usually prepare themselves to breast-feed their babies, the possibility to do so diminishes the difference between the dreamed-of child and the real child.

In Crosstab Tables 8 and 9 we can see a comparison between bottle-feeding mothers that gave breast milk to their babies and bottle-feeding mothers that gave a surrogate (milk mixture) to their babies, and in Crosstab Tables 10 and 11 we can see a comparison between mothers that gave breast milk to their babies (either by breast-feeding them or by extracting milk with a breast pump) and mothers that gave a surrogate to their babies.

	Bottle-feeding		
Expressions of early bonding	Breast pump	Surrogate	**Total**
Only positive expressions	15	2	**17**
Both positive and negative expr.	3	2	**5**
Only negative expressions	4	3	**7**
No expressions	2	1	**3**
Total	**24**	**8**	**32**

Crosstab Table 8. Breast milk, milk mixture and expressions of early bonding. n = 32

	Bottle-feeding		
Expressions of early bonding	Breast pump	Surrogate	**Total**
Only positive expressions	15	2	**17**
Negative expressions	9	6	**15**
Total	**24**	**8**	**32**

Crosstab Table 9. Breast milk, milk mixture and expressions of early bonding, combined categories. n = 32

	Milk substance		
Expressions of early bonding	Breast or Breast pump	Surrogate	Total
Only positive expressions	23	2	**25**
Both positive and negative expr.	3	2	**5**
Only negative expressions	4	3	**7**
No expressions	2	1	**3**
Total	**32**	**8**	**40**

Crosstab Table 10. Relation between milk substance and expressions of early bonding. n = 40

	Milk substance		
Expressions of early bonding	Breast and Breast pump	Surrogate	Total
Only positive expressions	23	2	**25**
Negative expressions	9	6	**15**
Total	**32**	**8**	**40**

Crosstab Table 11. Relation between milk substance and expressions of early bonding, combined categories. n = 40

From these Crosstab Tables we can see that mothers that gave a milk mixture (instead of breast milk) to their babies seemed to have (proportionally) more problems with the early bonding process. The Fishers exact probability test determined that for Crosstab Table 9 the probability for such a distribution of frequencies under Ho is p = 0.07, which permits us to reject Ho. The same test gives us p = 0.021 for the distribution of frequencies in Crosstab Table 11.

These results can be explained (using ethological theories) as depending on hormonal differences between a mother who breast-feeds and a mother who gives a milk mixture (see page 52). On the other hand, the decision not to give breast milk to the baby was often based on very stressful family situations, in which the capacity of the mother to focus on the newborn baby with a cleft lip and/or palate was limited. Extracting breast milk with a breast pump would have added even more stress to the situation, so in these cases one can doubt if it would have facilitated the bonding process.

	Feeding difficulties		
Expressions of bonding	Yes	No	**Total**
Only positive expressions	14	11	**25**
Both positive and negative expr.	3	2	**5**
Only negative expressions	7	0	**7**
No expressions	2	1	**3**
Total	**26**	**14**	**40**

Crosstab Table 12. Relation between feeding difficulties and expressions of early bonding. n = 40

In Crosstab 12 we can see that every mother who expressed only feelings of rejection towards her child has a previous history of feeding difficulties [1]). All in all, 27 mothers express feeding difficulties. Again, this should not be interpreted so that if a mother has feeding difficulties, she will also have rejecting feelings towards her child. But in order to facilitate bonding processes, the parents and especially the mother, should get support and help when she is learning to feed her new-born baby.

---

[1] Note that the mothers that breast-fed their babies did not express feeding difficulties. They might have had some feeding difficulties, but they did not define them as such. This might also be a bias by the reseacher, since the world "difficulties" refers to real feeding problems that require a great deal of struggle by the parents. The mother of a girl with a small cleft in the soft palate, who succeeded in breast-feeding her baby, said that feeding took a long time, but she was so happy and proud and relieved about being able to breast-feed her little girl, that this was not defined as a feeding difficulty in this particular case.

Another conclusion is that the mothers should get help in order to allay the disapointment when breast-feeding is impossible. No social pressure should be placed on breast-feeding, and the mother should be taught how to bottle-feed her baby in a satisfactory way.

TABLE 10.

Mothers' Descriptions of the Weight-Gain of the Child

1. Good 25, 23, 27, 29, 32, 31,15,14,3,9,40,13,39,30,37,21		16
2. Not good 28, 33,17,16,4,11,10,2,18		9
3. Problems at the beginning, then normal 34, 22,19,12,8,7(6 months)		6
4. Very good 36, 24,5,1		4
5. Somewhat slow 20,26		2
6. No description 35,38,6		3
	Total	*40*

Mothers' Descriptions of the Weight-Gain of the Child

From Table 10 we can see that 20 of the mothers estimated the weight of their children as "very good" or "good", while 17 mothers described the weight gain of their children as not so good. This question was not asked in order to estimate the factual weight of the child (even if this was considered during the study), but in order to find out if the weight-gain was a source of stress for the mothers. Most studies indicate that the birth-weight is lower in cleft children than in the general population. There is also a lag in the weight-gain, compared to normal children (Seth & Mc Williams 1988, Nyström, Ranta & Kataja 1992).

However, the estimate of the mothers of the weight of their children is consistent with results concerning feeding problems in this study: mothers of children with a cleft lip (and no problems with feeding) consider the weight-gain of their child as good (Crosstab Table 13).

	Cleft type			
Mothers estimate of weight-gain	CPO	CLP	CL	**Total**
Good	5	8	7	**20**
Initial problems	2	4	0	**6**
Not good	7	4	0	**11**
Total	**14**	**16**	**7**	**37**

Crosstab Table 13. Relation between cleft type and mother's estimate of child's weight-gain. n = 37

In Crosstab Table 14 we can see the relation between the expression of early bonding and weight-gain.

	Expressions of early bonding				
Weight-gain	Positive	Both Positive and negative	Negative	No exp.	**Total**
Good	14	2	4	0	**20**
Initial problems	5	0	1	0	**6**
Not good	3	3	2	3	**11**
Total	**22**	**5**	**7**	**3**	**37**

Crosstab Table 14. Relation between expressions of early bonding and mother's estimate of child's weight-gain. n = 37

As mentioned in Chapter 1, Epoché, there might be a link between failure to thrive and maternal deprivation: the interaction between an infant and his mother in feeding situations might have an impact on the weight-gain of the child. Crosstab Table 14 shows that there is proportionally more infants with a poor weight-gain in the categories of negative bonding patterns. Even if the observed frequencis does not differ much from the expected frequencies (based on the null hypothesis), this result might be seen as emphasizing the importance of the early bonding process for the child's well-being.

TABLE 11.

MOTHERS' DESCRIPTIONS OF SEPARATION

1.Mothers' Feelings About Surgery

1. I was impatient 23, 24, 33, 32, 20,19,17,14,2,12,6,5,1,40,37,21,8,28,3	19
2. I did not recognize the baby after surgery 28, 29, 33, 32, 22,16,5,9,26,7,9	11
3. I was nervous 34,15,16,40,35,39,21,8,9	9
4. Afraid because of the risks (the baby will die) 36, 34,18,6,35,39	6
5. A shock when I saw the baby after surgery 27, 33,10,38,37,21	6
6. Worse than when the baby was born 25,40,38,30,37	5
7. I was not nervous 4	4
8. I had a breathing spell 31,22,5	3
9. It was difficult to leave the baby at the hospital 3,13	2
10. Surgery did not change the child's appearance 11	1

2. Mothers' Staying with the Child at the Hospital

1. Stayed the whole day with the child 25, (24, 33 both), 27, 28, 34, 29, 32,22,18,5,9,35, 20,19,17,15,16,14, (12, 6, 13,21 wanted at first to stay at night, but did not mind going away),8,40,39,30,37,1, 10 26		31
2. Stayed or wanted to stay day and night with the child 11,2,38		3
3. Visited the child every day, but did not stay all day 23,7,4		3
4. Left the child at the hospital 36, 31		2
5. Stayed with the child part of the time 3		1
	Total	*40*

3. Other Experiences of Separation

1. No other experiences 1, 5,6,8,9,10,11,12,13,14,16,19,18,20, 21,22,23,24,25,15,28,36,37,40,30,27,35,38		28
2. Separation after birth 2,3,7,17,26,31,32,33,34, 39		10
3. I have been on a trip 29		1
4. No description 4		1
	Total	*40*

Mothers' Descriptions of Separation

In Table 11.1 it is interesting to note that even if the change in the child's appearence is expected and wished for, it might nevertheless be a shock for the mother: she does not recognize her own child before she discovers that the child recognizes her. A total of 17 mothers felt this way. Among these mothers, there was also one mother of a girl with a cleft palate only: she felt that the palatal closure changed the appearance of her child very much, when another mother of a girl with a cleft palate was disappointed that the surgery did not change the appearance of her child. Almost half of the mothers (19 of 40) had been impatient, wanting to accelerate the process, but on the other hand 12 of the mothers had been afraid of the surgery.

In Table 11. 2 we can see that the most typical pattern is that the mother stays with her child at the hospital (31 mothers out of 40), but would not like to stay at the hospital at night. However, 4 of these mothers said that they first wanted to stay at night as well with their child, but that they soon realized that it would be too heavy for them. Only 3 mothers wanted to stay night and day at the hospital, and of them one mother got the permission to do so.

Only 2 mothers left their child at the hospital, and they were both of the opinion that it made no difference to the child: *"I knew that a three-months-old baby could not really miss his mother"*. One of the mothers also said that she needed to rest at that point, because she was so tired. It is important to notice here that the mother has the right to feel so, and that it might have been the proper solution in her case: maybe she was a more responsive mother after a week's rest than she would have been otherwise - after all, at the time of the interview she was staying with her child at the hospital (this was the third surgery).

(However, during one of my seminars, this case raised the question of whether the researcher should act as a teacher and tell the mother that she ought to stay with her child. My personal solution to this is that, at least during the interview, it does not fit the role of the researcher to start acting as an expert in child-rearing. It might be more valuable for the interviewee to have somebody listening to her with respect to her feelings and solutions. This is also a question of ethics. But if the child is maltreated or the mother seems to be helpless in one way or another, the researcher can and should offer help to the family. As mentioned earlier, in one case such help was offered.)

All in all, the surgery and the time at the hospital is described as a very difficult time for the family: *"I knew that he would have pains and such things, but I did not know about my own feelings, how terrible it would be"*. But on the other hand, the mothers also felt that it was valuable to meet other families in the same situation, and to meet doctors and nurses who know a lot about the cleft palate problem; to be the receiving party in a counselling situation.

In Table 11. 3 other experiences of separation are listed. Ten out of 40 mothers had experiences of separation from the baby for up to one month after the delivery, which is astonishing, since the children were healthy and only two were classified as prematures. The reason for separation was usually due to feeding difficulties, and the separation was usually very difficult for the mother: *"And then these horror things started to happen. First of all, I didn't get the baby./ She was kept in the nursery and when I asked for her, they did not give her to me./ And then I don't remember anything, I was probably alone in my room and probably was crying"*

Possibly the hospitals tend to be extra careful with a new-born with a cleft lip and/or palate, in order not to create any more problems for a child who already has a malformation. However, since we know that it is not recommendable to separate newborns from their mothers, since it might disturb the early bonding process (see for example Klaus and Kennel 1976), the recommendation here would be to consider very carefully whether it is necessary to separate the child with a cleft from his mother. Otherwise, the result may be to add one more disturbing factor to a bonding process that is potentially already disturbed. In Crosstab Table 15 we can see the connection between separation after birth and early bonding. There is a slight over-representation of mothers who were separated from their babies after birth in the group that expresses difficulties in early bonding, which adds more weight to the conclusions above.

	Separation after birth		
Expressions of early bonding	Non-separation	Separation	Total
Only positive expressions	20	5	**25**
Both positive and negative expr.	4	1	**5**
Only negative expressions	3	4	**7**
No expressions	3	0	**3**
Total	**30**	**10**	**40**

Crosstab Table 15. Relation between separation after birth and expressions of early bonding. n = 40

TABLE 12.

Mothers' Expressions of Emotions During the First Year

1. I was (for a long time) afraid of additional problems 1,2,26,28,36,34,31,20,17,38,19,16,37,33,27,10,25,24,23,14	20
2. After half a year suddenly strong negative feelings arose such as hate, envy or depression 27, 34, 22,15,14,1,40,35,26,28,25	11
3. Why did it happen to me? 2,5,23,24,29,31,34,32,38	9
4. I was over-energetic and strong in the beginning 1, 6,22,15,24,26,27,34	8
5. I have been bitter 32, 31	2
6. I have been very depressed 31,21	2
7. I never became a woman 11	1
8. No use to ask "why me?" 39	1
9. I prepared myself to have to give the baby away 16	1
10. I built myself a prison and punished myself for my failure 11	1

Note: Figures refer to the number of mothers who gave a response in each category. Hence totals do not add up to 40.

Mothers' Expressions of Emotions During the First Year

This table was maybe the most difficult to label. It offers descriptions of some of the feelings that the mothers chose to talk about during the interview. Some of these feelings could be interpretated as coping behavior as they seemed to be on a more conscious level. (Coping behavior is often defined as an activity in which a person engages to manage one's reactions to unwanted discrepances between what he wants to happen and what is actually happening (Ostell 1991, 11 - 13)). An example of this is the description that 8 of the mothers gave me about being over-energetic and even pretending to be strong in the beginning: *"After the first day of crying I took a very strong role...and I kept it for a long time, through the whole spring, a laughing, smiling, surely-I'm-going-to-manage- this-role, but in the summer I started to feel weak and I sort of fell off."* Another side of the same coin is on a more subconscious level, when the mother after half a year, or some months, suddenly gets very depressed without understanding her own feelings or without any explanation of why this happens.

In Tamminen's study (1990, 103), clinical depression of a more permanent nature occurred in 12 % of the mothers. According to her, it has been convincingly established that postnatal depression has detrimental effects, particularly on the infant's early socio-emotional development.

The aim of this study was not to find out how many of the mothers had experienced clinical depression. However, the majority of the mothers reported feelings that they interpreted as negative: bitterness, depression, anxiety. We do not know how many of the women would have had such feelings anyway, but there is good reason to believe that the fact that the baby had a cleft had an impact on the frequency of these feelings in this material - usually the postnatal period is a time of satisfaction and happiness for the mother (Tamminen 1990, 103). This can be compared with the results from a study by Marks (1980), where the discrepancy between expectations and reality was significantly greater among depressed mothers than among non-depressed mothers. Depression might be a way to handle this disappointment.

Therefore, an important practical concern is to consider mothers of infants with a cleft as belonging to a risk group for postnatal depression and to provide early support for these families.

Typical in the case of a child with a malformation is also the question "Why me?" and the feelings of envy and bitterness that have been described earlier in Chapter 3. It is also worthy to note that 20 of the mothers were afraid of additional problems for a long time, despite the fact that the babies were otherwise perfectly healthy. One can actually ask how much of the stress the mothers felt was due to the factual malformation, the cleft, and how much to the fear of additional problems. Here also we can find possibilities for intervention by reducing the fear of additional problems by informing the parents about the cleft palate problem.

Signs of a narcissistic injury (see pages 10 and 46) may also be noted here, for example in the sad expression "I never became a woman".

TABLE 13.

The Information the Mother Got at the Hospital

1. Got yellow booklet 36, 24, 28, 29,33,32, 22,17, (18,16 but I did not read it), 11,12,8,5,9,40,38,13,39,37,10	21
2. No, or practically no oral information 25, 23, 28, 31,19,14,11,3,35	9
3. No information about feeding the baby 27, 23, 25,19,16,3,9,37	8
4. Got information about feeding the baby 22,17,15,14,2,8,18,4	8
5. Got information from contact-person 28, 29, 34, 32,5,1,21,10	8
6. Wrong information of the time/place of the surgery 36, 29,19,13,37	5
7. Got information about time/place of the surgery 15,2,12,8,6,40,30,4	5
8. Wrong information about feeding the baby 34,20,11,1	4
9. Satisfied with information 7,5,39,26	4
10. Got old booklet 27, 34,11	3
11. Other wrong information 22,16	2
12. Knew about cleft 6	1

Note: Figures refer to the number of mothers who gave a response in each category. They could give more than one response, but every mother gave some response. Hence totals do not add up to 40.

The Information the Mother Got at the Hospital

When examining the information the mothers received at the hospital when the baby was born, it is interesting to note that even if the cleft palate problem is a common one in Finland, the mothers felt that they were poorly informed about the problem. Only 4 mothers expressed satisfaction with the information they were given. Nine mothers felt that they did not get any oral information at all. Twelve (different) mothers were given wrong information of some kind, and a total of 12 mothers were given either no information or wrong information on how to feed their babies.

In this sample, 27 (of 45) different hospitals are represented, and there is no reason to believe that the sample is not representative for the population. No doubt there are possibilities for intervention in this area. The need for more information immediately after the delivery is clear.

4.2 Maternal-Infant Bonding and the Cleft lip and Palate Problem

So far in this study the results confirm that feeding problems might disturb the early bonding process. But how strong is the impact of these problems? Can one overcome them? As we can see from the following Tables (Table 14 and 15), most of the mothers bonded with their babies. In Table 14 a and b, we can see the mothers grouped according to how they felt at birth and according to the bonding process, with the feeding technique as an intermediate factor. *The feelings at birth* are classified with mixed feelings at birth being given the value 0 and negative feelings at birth being given the value -1. This is only a qualitative classification to be able to compute the values. *The feeding technique* is classified with breast-feeding being given the value 1, breast-pump the value 0 and milk mixture being given the value -1. *Bonding* is classified with only positive expressions being given the value 1, mixed expressions the value 0, and only negative expressions the value -1. Table 14 a and 14 b differ from each other with Table 14 a showing only the mothers that expressed mixed feelings at birth and Table 14 b only the mothers that expressed negative feelings at birth. This division should facilitate the reading of the tables.

Grouped Mothers	n	Felt at birth	Feeding tech.	Bonding
M 13, 30, 38, 39	n = 4	0	1	1
M 2,12,15, 22, 25, 27, 29	n = 7	0	0	1
M 5, 17	n = 2	0	0	-1
M 9	n = 1	0	-1	1

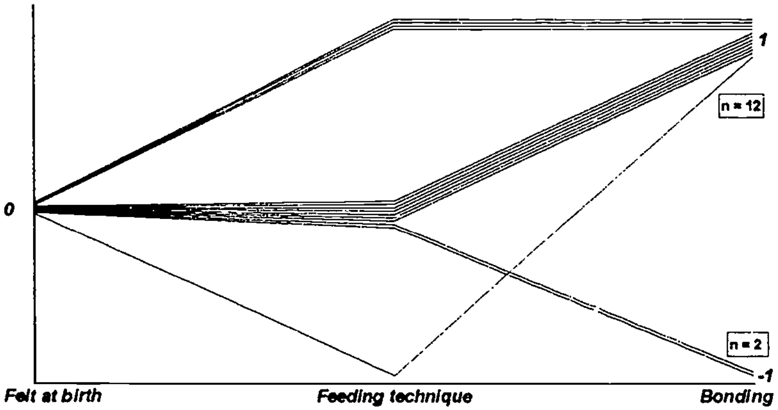


Table 14 a. Profile of the bonding process with feeding technique as an intermediate factor (mixed feelings at birth). n = 14

Grouped Mothers	n	Felt at birth	Feeding tech.	Bonding
M 21, 35, 37, 40	n = 4	-1	1	1
M 3, 6, 8, 11, 14, 19, 24, 34	n = 8	-1	0	1
M 1, 10, 20, 28, 33	n = 5	-1	0	0
M 16, 31	n = 2	-1	0	-1
M 26	n = 1	-1	-1	1
M 4, 18, 36	n = 3	-1	-1	0
M 7, 23, 32	n = 3	-1	-1	-1

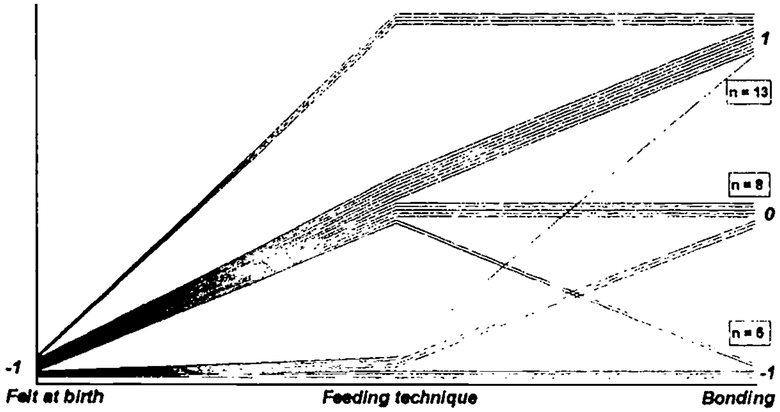


Table 14 b. Profile of the bonding process with feeding technique as an intermediate factor (negative feelings at birth). n = 26

From these tables we can see that a total of 25 mothers (12 in Table 14 a and 13 in Table 14 b) expressed only positive bonding with the child. We can also see that among the mothers that expressed negative feelings at birth (n = 26), 7 mothers decided not to give breast-milk to their babies, while only one of the mothers that expressed mixed feelings at birth (n = 14) decided not to give breast-milk to her baby. The majority of the mothers expressed positive early bonding. The interest must therefore be focused on the mothers (n = 15) that report problems with early bonding: are there any repeated patterns, and is there possibilities for intervention?

One repeated pattern, that is shown by Tables 14 a and 14 b, is that no mother that had breast-fed her baby expressed only negative bonding. Usually there were no possibilities for intervention here, since the possibility to breast-feed a baby is highly dependent on the cleft type of the infant.

Tables 15 a and 15 b show the development profile of the maternal-infant bonding process, with feeding difficulties as the intermediate factor. No difficulties is given the value 1, moderate difficulties is given the value 0 and severe difficulties the value -1. Table 15 a shows the mothers with mixed feelings at birth, and 15 b shows the mothers with only negative feelings at birth.

Grouped Mothers	*n*	*Felt at birth*	*Feeding diff.*	*Bonding*
M 13, 29, 30, 38, 39	n = 5	0	1	1
M 9,12,15, 22, 25, 27	n = 6	0	0	1
M 5, 17	n = 2	0	0	-1
M 2	n = 1	0	-1	1

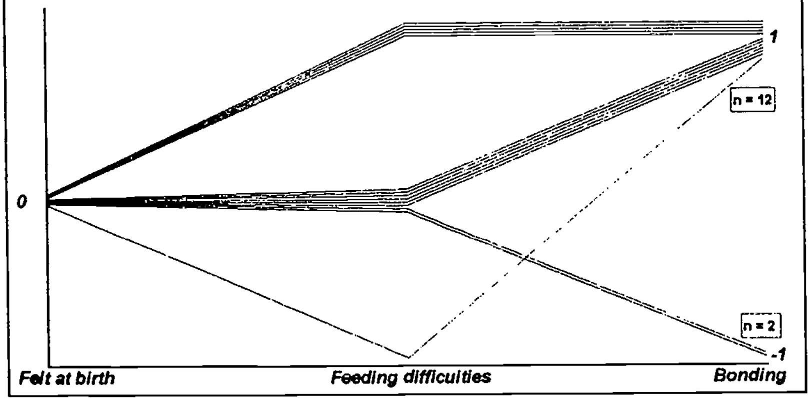


Table 15 a. Profile of the bonding process with feeding difficulties as an intermediate factor (mixed feelings at birth). n = 14

Grouped Mothers	*n*	*Felt at birth*	*Feeding diff.*	*Bonding*
M 6, 14, 21, 35, 37, 40	n = 6	-1	1	1
M 4, 33,36	n = 3	-1	1	0
M 3, 8, 11,19, 24, 34	n = 6	-1	0	1
M 1, 18, 20	n = 3	-1	0	0
M 7,23,31,32	n = 4	-1	0	-1
M 26	n = 1	-1	-1	1
M 10, 28	n = 2	-1	-1	0
M 16	n = 1	-1	-1	-1

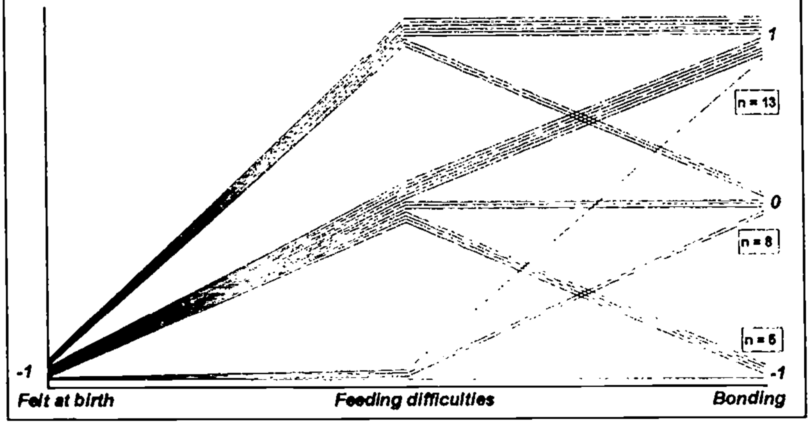


Table 15 b. Profile of the bonding process with feeding difficulties as an intermediate factor (negative feelings at birth). n = 26

From these tables we can see that every mother that expressed only negative early bonding had moderate or severe feeding difficulties. These tables illustrate the same thing that was found in the Crosstab Tables: breast-feeding is a good base for positive early bonding, and every case of negative early bonding has a previous history of feeding difficulties. However, they also show that we find positive early bonding in every group of mothers: we may find mothers with severe feeding difficulties that expressed positive bonding. This means that we are not dealing with causal relationships.

4.3 Summary of Results

The main idea in this step of the phenomenological method was to find invariant features of the phenomena under study. During the first stage, my own pre-theoretical understanding, as well as the prevailing theoretical understanding of the problem, was articulated. This understanding was bracketed and the conclusions drawn from the theoretical knowledge about the cleft palate problem were examined carefully.

This theoretical knowledge could be thematisized and formulated as certain claims, important in a study that deals with maternal-infant bonding issues. The claims, derived from theory, were the following:

1. **It is more difficult for the parents to accept the situation, if the defected child is their first child.**
5. **Early maternal-infant bonding might be disturbed if the child has a visible malformation.**
6. **Early maternal-infant bonding might be disturbed if breast-feeding is impossible.**

Claims number 1 and 6 get support in this study, while claim number 5 does not get particular support. It seems that claim number 5 depends heavily on the severity of the malformation. A small cleft lip is not considered a big problem for the mothers, especially if breast-feeding is possible.

The main result is: in this study, a defect that interferred with feeding disturbed the early maternal-infant bonding process more than a defect that only interferred with the child's appearance.

In a crucial test between the importance of a visual defect versus a functional defect, the results show that in the life-world of the mothers, the functional defect was considered more overwhelming.

This result does not correspond with those of Spriestersbach (1973). According to his study, the greatest reactions occurred among mothers of children with cleft lip and palate, less with cleft lip only and least of all with cleft palate only. Their conclusion is that these reactions mainly give credence to the notion that in the American culture appearance has a high symbolic value. (Spriestersbach 1973, 63.)

Previous studies and pre-theoretical knowledge implicate that the cleft lip problem is more difficult to accept. In this study, the cleft palate, with or without cleft lip, was considered as a more severe problem among the mothers. This result is new, and will give new directions for initial information and intervention processes.

The result of this study gives credence to the earlier-mentioned notion that in our culture breast-feeding seems to have a high symbolic value. However, the first reaction to the cleft must be distinguished from the difficulties that arise later. The feelings at the child's birth might be more overwhelming when the child has a severe cleft lip and palate than when the child has a small cleft of the soft palate. But soon the feeding problem, when it is severe, seems to take over. This was also noted in Spriestersbachs (1973) study on the parents of 140 children with clefts: "The one exception to this pattern (that the visual defect is difficult to accept) is the frequency of mothers of the children with cleft palate only being overwhelmed by the problem. Although these children have no cosmetic problem, they frequently do have other conditions which are prejudicial to survival, particularly the feeding problem "(Spriestersbach 1973, 63).

Spriestersbach offers no explanations for his findings. The results in this study can be interpreted so that a visual defect disturbs the bonding process mechanically (the baby looks different). When the mother gets used to the appearance of her child, this effect disappears. The functional defect disturbs the bonding process in a dynamical way: the baby acts differently and this disturbs the interaction between the baby and his mother. Thus this defect may have a long-term effect on the maternal-infant bonding.

The other findings are the following:

1. The birth of a child with a cleft is considered a shock by most mothers.
2. The most severe problem has been the feeding problem.
3. Surgery, even if wished for, is considered as a shock by most of the mothers.
4. Feelings of depression, fear, or bitterness are common among mothers of infants with a cleft.
5. The information that the mothers received at the hospital when the baby was born was inadequate.

These findings have been used in creating supportive systems for the families, described in the next chapter.

4.4 Summary of Recommendations for Nursery Care at the Delivery Ward

The most important thing for the personnel in the delivery ward is to facilitate the bonding process between the parents and their baby. Therefore, the following recommendations can be summed up:

1. To give correct information as soon as possible to both of the parents, and to repeat it. The information should be given in a positive way, using both verbal, visual and written material. The positive prognosis for complete rehabilitation (with a rapid start during the first months) should be emphasized. The child should be focused on as a whole, with an emphasis on normality and on the positive features the child has. Possible additional problems should not be presented until confirmed. On the other hand, if there are other problems, the parents have the right to be informed promptly.

2. To encourage and help the mother (parents) to find a positive and satisfactory feeding pattern, to diminish the disappointment the mother might feel when she learns that she might not be able to breast-feed her baby. Feeding problems must be identified, not only as a technical problem to be solved, but as a problem with a significant impact on the early bonding process between the mother and her infant.

3. To give the parents a possibility for intial contact with the baby, since any period of delay heightens their anxiety. To avoid separation and tube-feeding (if it is possible) and other things that add more stress to an already stressfull situation.

4. The personnel should be sensitive to the needs of the family and offer flexible solutions. The family should also be offered a possibility to talk about their feelings and to ask questions.

It is also a fact that the psychosocial problems a cleft lip and/or palate creates are seldom catastrophic in our culture. But they need to be recognized, because if the parents get the support they need, the psychosocial problems related to a cleft can be reduced.

5. CREATIVE SYNTHESIS: IN SEARCH OF MEANING

So far in this work the rules of the phenomenological method have been followed, and step by step the invariant features of the problem have been reached: the *essence* of becoming the mother of a child with a cleft. The purpose of this chapter is to go beyond facts, in order to reach the meaning. This also means that *existential* aspects of cleft will be illuminated.

In this study the starting point was the immanent experiences of the mothers, their subjective, internal experiences of cleft (Chapters 2 and 3 of Part II). Then the perspective shifted from the immanent to the more transcendent, which in this study is the intersubjectivity, the experiences-in-common, experiences that can be lifted up to an external level (Chapter 4). Now is the time for a synthesis, which is a product of the understanding of the phenomenon in this study reached by examining, in a dialectic way, both theories and immanent and transcendent aspects of cleft in a dialective way.

In this chapter I will focus on a few themes only. The first theme, the definition of crisis, became interesting because the mothers experienced the occurrence (becoming the mother of a child with a cleft) in many different ways. The second theme, the child in the mirror, became of interest purely through the interviews. The third theme, the meaning of the occurrence, was also something that the mothers wanted to talk about. They asked themselves the question "Why me?", and they also answered themselves. The last theme is what is here called "the loving-more dimension"

5.1 On Becoming the Mother of a Child with a Cleft

The Concept of Crisis

The first thing to re-examine is the definition of the occurrence itself. In crisis theory, here represented by Cullberg, the birth of a defected child is a traumatic crisis (Cullberg 1979), and if the child is the first one, the traumatic crisis is combined with a developmental one. The crisis may be conceived of in terms of a series of stages. The stages also include descriptions of defense mechanisms, and one defense mechanism is known to be *denial* (Cullberg 1979; Belfer et al. 1982, 311). No doubt, there is a possibility of denial when an interviewee does not express any feelings of disappointment or sorrow when talking about the birth of a child with a cleft. The attempt here is not to deny the possibility of denial, but to add a little more flexibility to the concept of crisis and to avoid static, pattern-bound conclusions.

The argument then is that the same occurrence is not automatically interpreted in the same way by different persons. Hence the birth of a child with a cleft is not necessarily a crisis for every mother, and in consequence the occurrence will not lead to identical reactions for different persons. The point is that in order to be able to deny a crisis, there must be a crisis in the first place. Thus, the definition of a crisis in this study will emphasize that it is not the occurrence *per se* that causes the crisis. The concept of crisis can be used only when three different components are co-existing on the same time. The *first component*, and the basis, is the occurrence, in this case the birth of a child with a cleft. The *second component* is the personal interpretation of the occurrence, which might include the feeling of loosing control over one's life, to be deprived of a part of one's autonomy (Habermas 1984,157 - 158).The *third component* is dependent on the first two components, and can be described in reactions to the occurrence organized over time, including both emotions and acting. Typical for the third component is an incapability to act rationally and make decisions, and a "flooding" of feelings that the person is incapable of controlling. (An example of this is starting to cry when somebody asks "how are you?") (Hillgaard, Keiser & Ravin 1990, 66.)

The implications of this model are that only if the mother interprets the birth of a child as a crisis, is it a crisis for her. This position is actually shared by the situational orientation to the source of parental reaction, described by Ferguson & Ferguson (1987) as the psychosocial position. In this material two groups of mothers had a tendency not to define the occurrence as a crisis. The first group is the group of 8 mothers who were able to breast-feed their babies. They expected that they would be able to breast-feed their babies, and they were. Thus, the defect that their baby had did not disturb very much their picture of or previous experiences of mothering, and they apparently did not feel that they lost control over their lives. In consequence, the occurrence was not interpreted as a threat. This can be compared with the mothers who were very disappointed because they could not breast-feed their babies, and with the mother that expressed feelings of not becoming a woman, because she could not breast-feed her baby. As we can see, the result in Chapter 4 that a defect interferring with feeding disturbed the early maternal-infant bonding process more than a defect that only interferred with the child's appearance, may also be interpreted in the light of crisis theory.

The other group that did not define the occurrence as a crisis was the small group of 4 mothers of which 3 had lost another child: one was still-born, another lost her child in SIDS (Sudden Infant Death Syndrome) and the third lost her child from malignancy. The fourth mother had very serious problems within the family at the time of the birth of her child with a cleft, and did not notice the cleft nor the child because her thoughts and actions were pre-occupied with these other problems.

This interpretation respects the mother's right to define an occurrence or not as a crisis for her, but it does not deny the possibility of denial. As has already been pointed out, this interpretation of the crisis concept only offers more flexibility to it and helps to avoid rapid conclusions: the tendency to define or not define the birth of a baby with a cleft as a crisis is apparently dependent on the different life-worlds of the mothers.

One final remark: In this study the mothers who were able to breast-feed their babies did not *express* difficulties to bond. This should not be interpreted as if they *had* no difficulties, but they had a tendency not to express such difficulties. Furthermore, as has already been pointed out in Chapter 4, this result should not lead to a recommendation to encourage mothers to breast-feed their babies. Such a recommendation would put even more pressure on the mothers who are not able to breast-feed their babies The conclusion here is that when breast-feeding is impossible, the mothers should get support to make the decision to give it up. They also need support to express their feelings of disappointment and to accept the situation as neither their nor the infant's fault

Some mothers seem to be proud of their capacity to extract breast-milk with a breast-pump. Extracting milk with a breast-pump might therefore be a solution for a mother that is disappointed because breast-feeding is impossible. But if a mother decides not to give breast-milk to her baby, that is her decision, and no pressure to go on with breast-pumping should be put on her: an exhausted mother might be more un-available for her child, and thus breast-pumping might create more problems than the decision to give a surrogate (milk mixture).

The Child in the Mirror

The tendency to hide a child with a visual cleft has been interpreted as a sign of stigma (Goffman 1968). Stigma refers to the (bodily) signs of being different that also (usually) carry a negative moral evaluation. The mark may or may not be physical. A stigmatized person may be retarded, crippled, ugly, alcoholic or a member of an ethnic outgroup (Atkinson, Lindzey & Thompson 1984, 5). In the case of a child with a cleft, the question to be asked is: who is the stigmatized individual? No doubt the child carries the stigma, the visual "mark". The tendency to hide the child can then also be interpreted as a sign of shame (and the mother is then stigmatized as being the mother of a defected child). Some writers have suggested that shame is public, while guilt is private. However, shame also has two dimensions: one can be ashamed of oneself, or one can be ashamed of another person. To be ashamed of another indicates a tie with that other, even a responsibility (Giddens 1984, 55). The different dimensions of stigma have been described as the following (Farina 1984, 24):

1. *Concealablility*: is the condition hidden or obvious? To what extent is its visibililty controllable?

2. *Course*: What patterns of change over time are shown by the condition? What is its ultimate outcome?

3. *Disruptiveness*: Does it hamper interaction or communication?

4 *Aesthetic qualities*. To what extent does the mark make the possessor repellent, ugly or upsetting?

5. *Origin:* Under what circumstances did the condition originate? Was anyone responsible for it?

6. *Peril:* What kind of danger is posed by the mark, and how serious is it?

The first dimension, that of concealability, varies among different types of cleft. The question arises: which condition is more difficult for the mother, the visual or the "invisible" cleft? The child is marked if the cleft is visible, and the mother has to go through the whole process with stigma, shame and guilt. But even if a "mark", in this case a cleft palate only, can be successfully concealed, we must not conclude that it will have no effect on interpersonal relationships. The feelings of guilt remains, the cleft remains, even if not visible, and to that we can add the fact that a mother that decides to conceal the cleft cannot communicate her feelings to her relatives and friends. So even if a cleft palate is only less stigmatizing for the child, it can be very difficult for the mother to handle. We have also seen such examples in this study.

The effort to change the course of the cleft is usually not initiated by the affected individual. The family is mainly responsible for course shifts, and it seldom happens in our society that the family would refuse to let the child go through surgical procedures. On the contrary, in the beginning many of the mothers were very impatient. Later, the adult with a cleft can decide whether or not he or she is willing to go through further surgeries.

Any condition that has the capacity to call attention to itself, and away from other characteristics ot the other person, is disruptive. Disruptiveness occurs when a nonstigmatized member is placed in a conflictful and uncomfortable state (Farina 1984, 49). For example, a person that sees a baby with a cleft lip and palate wants to stare at the baby, and yet adhere to the social norm of not staring. To reduce this conflict, they avoid talking to a mother of a baby with a visual cleft. Or, if not so sensitive to social norms, they stare at the baby and through this behavior they hurt the mother's feelings. Later, the dimension of disruptiveness also includes possible articulation and other communication problems that the individual with a cleft palate may have.

Disfigurements such as distorted facial figures, may dramatically affect how attractive someone is to others. Several studies suggest that an aesthetic factor is responsible for the social rejection of people with marks. There are also studies that suggest that the self-esteem is correlated with how attractive people imagine themself to be, and that the face seems to be the crucial body part (Farina 1984, 50, 54).

The dimension of origin touches upon issues of responsibility. In the case of the baby with a cleft palate, the mother might feel that she is responsible for the cleft and therefore feel guilt. There is also some evidence that supports the expectation that a person suffers more from a stigma when he feels responsible for it. But this dimension is also important in a social context: if the relatives feel that the mother is responsible for the child's cleft, she might be less favorably evaluated (and receive less help). One explanation for this is that when people see that other people have problems or are suffering, that makes them feel guilty, and to reduce this feeling they conclude that the sufferers must deserve their fate, having brought their misfortune upon themselves through sin: the process of blaming the victim (Farina 1984, 59). We have also seen examples of this in the present study.

The last dimension, peril, focuses on dangers posed by stigmatized individuals. In the case of a cleft palate, this dimension is not very relevant. Still, the sight of a baby with a cleft lip and palate might arose the fear, among the observers, that the same thing could happen to them; that they or their relatives might give birth to a child with a cleft.

As we can see, the mother of a child with a cleft often has to carry both feelings of guilt ("It's my fault") and feelings of shame for the child, who is stigmatized. She might also feel stigmatized herself. In some cases it is also possible to conceal the "mark", the cleft. Besides these feelings, she is also sensitive to other social norms: a good mother should not be ashamed of her own child. So she might be ashamed of the child - and also ashamed of the fact that she is ashamed of her child, that is, ashamed of herself.

One mother, a sociologist, also interpreted her own behavior in this way (she has a girl with a bilateral cleft lip and palate):" *Somehow I had a bad conscience about avoiding (to show the child), because I had earlier been preaching so much about being different (laughing) and about how one should take an open attitude towards a disability and not conceal it...and I did exactly what one should not do."*

This situation is indeed very complicated. However, my attempt here is to make it even more complicated by introducing one more dimension of the problem concerning stigma and shame. In the same interview the mother (above) talks about the same matter in a quite different way: " *Somehow I connect with this a wish to protect the child, that how can you, you old hag, come and say such things about my child. I got hurt because of my child, when I loved her and I found out how wonderful she was, and I could not possibly understand how somebody could have the right to come and say that my child looks very odd.* "

Hence the same situation can apparently be interpreted as either a sign of stigma, or as protective behavior on the part of the mother, in order to protect the child and herself from being hurt by other people - or a combination of both.

In Table 16 we can see how common the tendency was among the mothers to hide or wish to hide the child

TABLE 16.

Showing the Child to Strangers

1. It was difficult, but I did not want to hide the child 25, 27,22,10,8,5, 39	7
2. People are staring at the child 29, 22,10,5,38,39	6
3. Did not take the child anywhere at the beginning 28, 31, 34, 33,7	5
4. People are curious 2,7,9,21	4
5. I felt ashamed, did not want to show 23	1
6. People felt pity for the child 36	1
7. I wish it would not be visible 24	1
8. I turned his head so that the clefted side would not be visibe 32	1
9. I was afraid that people would notice the cleft 16	1
10. No problems 40	1
11. I told the neighbor's kids that he had an accident 37	1
12. I did not feel ashamed 24	1

Note: 24 mothers in the study had a child with a visible cleft (CLP or CL).

Only one mother said that she never had any problems in showing her child to strangers. One of the mothers who had a child with a cleft palate (only) was also afraid that people would notice the cleft.

Here I would like to introduce the theories of Cooley, Mead and Laing. Cooley argued that a person's self grows out of a person's commerce with others, as a reflection (Coser 1977, 306). Cooley compared this to a looking glass; "Each to each a looking-glass". The notion of the looking-glass self is according to Cooley composed of three principal elements: "the imagination of our appearance to other people, the imagination of his judgment of that appearance and some sort of self-feeling, such as pride or mortification" (Cooley 1964, 184).

Mead introduces the distinction between the "I" and the "me". The self appears in social experience as a composite of the stabilized reflection of the generalized others in the "me" and the incalculable spontanety of the "I" (Mead 1972; Coser 1977, 339). The "me" has also been described as the sedimented bit of self, using a geological metaphor, which represents the constraints of the past, of tradition and culture, *of the shaping of the self by the other*; the community perspective of self, the object pole. The "I" is seen as the innovative, spontaneous, creative self, the immediacy of present, the subject self (Robinson 1987, 10; Rosenthal & Bourgeois 1991, 103).

We might then make a distinction between my direct view of myself, and what Laing calls a metaperspective, my view of the other's view of me. The stabilization of how I think you see me is then my meta-identity. The distinction of the two identities, my self-identity (my view of myself) and my meta-identity (my view of your view of me) are theoretical constructs, not concrete realities, but introduces the concept of *complementary identity* (Laing, Phillipson & Lee 1972, 5; Collier 1977, 95). The problem of a self-experience based on the assumption that others experience us is also touched upon in Sartre's *Being and Nothingness* (1977), and *shame* is seen as the clearest case of this mode of self-experience (see also Taylor 1987). (In fact, for Sartre even pride is seen as being built on the ground of fundamental shame - the shame of being an object for the other (Sartre 1977).

Now, in order to return to the cleft palate problem, I would like to introduce an extension of these theories. Cooley, Mead and Laing are concerned with the self- and meta-identity. But these theories are also applicable to the concept of "you", and we may also make a distinction between the "you", as I see you, and the "you" as "others" see you. The metaperspective here would be my view of the others' view of you. Hence, I have a direct view of you (I am looking at you), and a metaview of you (I am looking at how others are looking at you).

The mothers spontaneously expressed this in the interviews. They were able to look at the child through their own eyes (direct perspective), but they were also able to change their glasses and look at the child as others did (metaperspective). And, the most interesting of all, the mirror was for them the eyes of the others: when they looked at their own child through the mirror, the cleft became visible: *"When I look at the child through the mirror, I sort of see him in a more realistic way* "and *" In the mirror he looked different, I wondered if that's the way strangers see him?"* .

The mothers also expressed that because they had accepted the child, they expected others to do so, too - but that did not always happen. This point should also be penetrated. People do not accept the child, and how do they show it? They look terrified, or they look away, or they ask curious questions. They do not smile or talk to the child. Research has shown that small infants between 2 and 20 weeks react very strongly to a disturbed contact (Brazelton & Als 1979), and that most mothers instinctly respond to the child in a nurturant way. One of the most important things for the infant is to be reflected and to receive a positive confirmation (see for example Spitz 1965; Stern 1982; Rosén-Sandahl 1983; Winnicott 1983a; Winnicott 1983b; Igra 1987; Alveson 1989; Bettelheim 1989; Phillips, A. 1991; Trevarthen 1993). A child with a visual cleft can get this positive confirmation from his mother and father, but seldom from other people in his environment.

The tendency the mother has to hide the child might then originate from a wish to protect the child against signals in the child's environment that might be unnuturant or injurious to the child. Her behavior, even if on an unconsciuos level, protects the child against something that his self-in-development would not be able to handle, and thus her behavior is *functional* (protection) instead of *dysfunctional* (a sign of stigma). The result is, however, that the mother has a bad conscience for her behavior, whether functional or not.

This does not mean that the mothers would not have feelings of shame or that the concept of stigma would not be relevant here. But this opens a possibility to understand the difficulties the mother had to cope with, when the metaperspective of her child (the child as others saw him) was not in congruence with her direct perspective of their child (the child as she saw him). This might also implicate that there may be a transition over time from the dysfunctional behavior to the functional: before bonding occurs, the mother might have feelings of shame, but when bonding occurs, her feelings are mostly protective.

The Meaning of the Occurrence

When something happens that a person does not wish to happen, a very common question asked is: Why me? There is, of course, no answer to that question. However, this question touches on existential aspects of life and might arouse further questioning on the same theme. Many of the mothers in this study had searched for a meaning for the occurrence, and had also created answers to the question "why me?".

TABLE 17.

The Meaning of the Occurrence

1. Improvement of my own personality and what is important in life 1,2,5,7,8,10,25,33,	8
2. I would like to help other people in the same situation 5,9,13,29	6
3. To come closer to God 2,28	2
4. I did not need this to develop, people develop without big adversities 10,38	2
5. Better that this child was born to us, because we can handle these problems 17,31	2
Total	*20*

In his work, Viktor Frankl has emphasized the will for meaning. His arguments are based on the concept of intention, as introduced earlier in the first chapter. In Brentano's thinking, intention is the directional mode of experience; in other words, people do not experience *per se*, they act intentionally. However, Frankl argues against the well-known motivation theory as described by Maslow. According to Maslow, people have different needs and on the top of these needs we find the need of self-realization. Frankl does not agree with Maslow on that point. He argues that self-realization is not the fulfillment of human life, nor is it the primary intention. Only if a person fulfills a meaning in her life, by working in the outside world, will she reach self-realization. But if she tries to realize her self - if that is her primary intention or her final goal- she will fail to do so. "Self-realization is the unintended result of the intention of life". (Frankl 1986, 43; Frankl 1990, 61.)

To be human is to direct the intention towards something else than oneself, to be what Frankl calls, self-transcendent. For him, self-transcendence is the "essence of existence" (Frankl 1986, 55). This is also the meaning of "meaning": when a person directs her intention towards something else than herself, she is in search of meaning, or creates a meaning out of the conditions of her existence. However, there is no universal "meaning of life" that people can lay back on, the point is that the unique meanings that people create are the real meanings for them.

In sociology, the *rational choice theory* is in opposition to the theory of Victor Frankl. This theory is based upon the assumption that people act only to maximize their own benefit and that they are interested in working for others only if they can profit from it. According to this theory, there are also a lot of so called *free-riders* in a society - people who try to benefit from the laurels of victory without taking part in the struggle. (Hellsten 1992, 155.) However, in all societies we can find feelings of solidarity, social norms and values that cannot be explained by the benefit for individuals.

Returning to the cleft palate problem, we can see that 6 of the mothers spontaneously said that they would like to help other families in the same situation, and 12 other mothers had found a meaning in the occurrence. Two mothers protested against these kinds of explanations, and said that people develop without big adversities in their lives.

However, the question "why me?" directs the intention towards a person herself and thus it is not self-transcendent. Among some mothers there is a transition over time of the question "why me?" to the question "why you?". This point is fundamental. The birth of a baby with a cleft is often - but not always - interpreted as an occurrence that happens to the parents, *they* have a baby with a cleft instead of the healthy baby they were expecting. However, they did not get the *cleft,* it is the baby who has to live with the cleft for the rest of his life. When the mother realizes that, she stops pitying herself and starts thinking of her child. What is now happening is in fact that she directs her intention towards her child and becomes what Frankl calls self-transcendent. And now she is grieving again, but not because of something that happened to her, but because of something that happened to her child. And this sorrow is deep, and in my personal belief might partly never be overcome. Thus her self-transcendation might hinder her acceptance, instead of improving it.

This feeling is in fact described by some of the mothers:" *I had the feeling in the delivery ward that I, myself, could have been torn apart in two pieces if only the child could have been healthy. Such a little thing, it's not right that such a little thing should have something happen to it."*

This mother felt that the cleft was something that "happened to" her child, but if the grief for the child is connected with feelings of guilt, if the mother is accusing herself for the cleft, the situation might deteriorate. (However, according to Frankl, it is a human perogative to have feelings of guilt and a duty to overcome them, which might be more easily said than done).

The conclusion of the discussion above is that there is no such thing as the meaning of the occurrence - but there are unique and personal meanings constructed by the mothers. Even the protest against a meaning is, if not a created meaning, at least a position. Furthermore, the self-transcendent position of the mother of a child with a cleft does not necessarily include a total acceptance of the occurrence. This conclusion cannot be proved by showing statistical facts, it can only be argumented for, and is discussed here in order to make different levels of acceptance and different positions among the mothers more intelligible.

The Loving-More Dimension

Give sorrow words
the grief that does not speak
knits up the o'erwrought heart
and bids it break

William Shakespeare

In Chapter 2, Part II, it was suggested that in order to become bonded with an infant with a malformation, the parents have to mourn the loss of the dreamed-for infant. This touches upon a paradox. In order to be able to accept a child with a malformation, one has to admit a non-acceptance. In order to want, one must reject. How can we explain such an idea?

No doubt, there are many possible explanations. Viktor Frankl uses the concept of *paradoxal intention*: to wish for something that you are afraid of, to decide to make something happen that you do not want to happen (Frankl 1990, 201). In this case the mother might be afraid of not being able to love her child (and so might her relatives). In some cases the mother tried to speak out about her feelings, and said straight-forward to her husband that she did not want the child or that she did not love her child. In this situation, the best support would have been to listen to the mother, and to respect her right to such feelings by being a mirror for them. Such a support would help the mother to accept her own rejective feelings, and later to bond with her child.

However, the relatives have to struggle with their own rejective feelings, and are therefore not always capable of giving the support the mother would need.

M: "...and I told my husband that I don't dare to attach to this child and he said, " don't go on like that, one can see how you like her", and I thought that, ohh o w terrible, how can someone else see things that I don't feel."

I: "So he couldn't accept that it was the truth, that you told him the truth?

M: "No, and at that moment I felt that I was totally alone, that if someone else can see things that I don't feel, then I would have to pretend the rest of my life...I think I have rejected the child all the time in order not to attach to her, because I have to give her away, and that's too heavy if I have to give her away. It is so easy to give her up if I never attach to her."

In this case the mother admitted her feelings to herself, and tried to talk about them to her husband as well. She felt she did not get enough support from him at the time, but she managed to handle her feelings of rejection and finally bonded with her child. In other cases, the husband had accepted the mother's feelings, and one way to handle them has been humor. Some families had internal jokes about their baby, and some of them were not suitable for ears outside the family. (One example of a humoristic approach to the cleft palate problem is the name of the magazine, published by the Cleft Palate Association in the USA, "Wide Smiles").

Humor is one dimension of specific human characteristics: the capability to dissociate oneself from oneself. When a person laughs at her anxiety, she has already found a remedy for it. (Frankl 1990, 202.)

But to return to the first suggestion: in order to be able to become bonded with a defective child, the parents have to mourn the loss of the healthy child. This statement is used in crisis theory (see Klaus & Kennel 1976). But is it to be handled as a fact or as a metaphor? In this study, both interpretations seem to be unsatisfactory. But even if I had the possibilty to compare mothers who really had lost a child to mothers who had not, the aim of this study was not to "measure" which experience was "worse". Still, even if the idea is used only as a metaphor, even if it is compelling and attractive, is it not a metaphor that maintains the myth of the perfect parent (Rapoport et al. 1977)? In this statement the feelings of mourning are felt for a child that does not exist, for the dreamed-of child that the parents lost. However, some of the mothers in this study at first rejected the child they had - and even felt that it would have been better if the child would not have been born, or if it would have died.

A more realistic statement, though not as compelling, would be that in order to be able to bond with a defective child, the parents may have to accept the disappointment that the very child gave them. The parents may be disappointed, or even feel that they hate the very child they had. But on the other hand, these feelings may change to the opposite, into attachment and love for that same child.

The mother will have to give up the idealized child; she may suffer from a narcissistic injury (Alveson 1989, 151). But how can we describe the quality of mothering that is based on the final acceptance of the real child? One mother described it this way:" *I don't know if it is so that one becomes more attached to these children because there is much more work with them. Apparently that is why the maternal love grows so much stronger, one want's to hold on to the child more. Sometimes I have to ask myself what's so special about --- compared to his sister ?"*

In this study a total of 9 mothers felt that they loved this child *more*, either more than their siblings, or more because of the cleft, or just more. At this point I would like to introduce the idea of the broken hammer. Sometimes the essence and meaning of things escapes us; and then they appear clearly to us, not when they function normally, but when they do not function. Heidegger introduces the idea of the broken hammer: we learn to know the essence of the hammer first when it is broken (Heidegger 1962). And furthermore: as long as it works smoothly, its meaning does not receive our explicit attention.

This does not mean that in order to get to know the real essence of mothering, one should first have a defected child. But it does mean that the birth of a defected child might add to the quality of mothering, based upon an acceptance of that child, a new dimension, a loving-more dimension. However, according to research done by Ferguson & Ferguson (1987) professionals tend to patologize the behavior of the parents: an example of patologizing is to interpret "overprotection" as "supressed hate". In this case, the loving-more dimension can be interpreted as overprotection.

The suggestion here is that the loving-more dimension, when it appears, should be respected as such. Alberoni (1979, 65) describes the love parents feel for a child with Downs syndrome: they know that their child is not like other children, but they do not love him less because of that. But in order to be able to love him they cannot compare him with other children; if they would do so, they would apprehend him as incomplete, worthless and their love would be a pity-love. But they give value to his specific perspective of the world. Because of their love, these parents have formed a new and different view of the world.

Possibly this dimension is not intersubjectively accessible to all people. This dimension will not appear to everyone who has a child with a cleft. But it is one dimension of becoming the mother of a child with a cleft.

5.2 Implications for Parental Education

5.2.1 Parental Education: Definition and Goals

Parenthood is a stage in the life cycle of the individual during which emotional growth and development continue. This is probably the most enduring joy of parenthood. It is an active joy, derived from doing, and different from the passive joy of receiving. The successful completion of this stage of life may lead to an increased ease in functioning in other areas as well. Experiencing parenthood cannot be seen as essential for the successful growth and development of an individual to maturity. The experience of parenthood does not either lead to achieving the goal of emotional maturity. But parenting gives the individual a possibilitiy to grow. (Rapoport et al. 1977).

Some components of parenting, like other skills, can be learned. Some elements of ideal-parenting activities such as "warmth" may be less amenable to learning than others, but some other components of caring behavior can be learned. The conventional assumption may be that every mother "naturally " knows how to care for and nurture children. Obviously there are conditions militating against this ideal, for example the condition that we have learned to know in this study. (Rapoport et al. 1977, 28.)

People cannot be commanded to love. But they can be taught how to care for a child. By making feelings of anger and guilt explicit as a part of what parents may have to learn to cope with, parents can also be taught how to deflect such feelings as not to overwhelm their knowledge of caring behavior. (Rapoport et al 1977, 28.)

The needs of the child must be in focus. Talbot has formulated premises of the needs of children (Talbot 1976, 171, as reported by Rapoport et al. 1977, 11):

1. Children must have such obvious material supplies such as food, shelter, clothing, medical care and other services designed to promote their bodily well-being
2. They must also have certain psychosocial supplies that nourish and nurture their minds and their spirits:

   a) being needed and wanted;
   b) being attended to, cared for and protected;
   c) being valued, accepted and given a sense of belonging;
   d) being educated and guided toward social capability; and
   e)being given opportunities for life satisfaction through useful work and creativity

Even if the need of the child must be in focus, the starting point must be the needs of the parents, the support they need to be able to achieve successful parenting. *Parental education* is one way to give that support to parents. As already pointed out in the beginning of this work, parental education is defined as nonformal education, charactarized as an organized and planned effort with a clear notion of aims and content. The ultimate goal of parental education is to have a beneficial impact on children.

5.2.2 Parental Education for Families with a Child with a Cleft

The main idea of parental education for "special parents" (Furneaux 1988) is to facilitate the adaptation process so that the parents will be capable of successful parenting. An adaptation process, however, can be defined as either 'constructive' or 'resigned' (Lahelma 1993, 9), where a constructive adaptation includes activity. This can be illustrated with the following figure (Hilgaard, Keiser & Ravin 1990, 75):

higher
level of functioning before a crisis ______ a crisis ______ same
lower
destroyed

After a major crisis, a person's level of functioning can remain the same as before, it may be lower or it can be higher (Hillgard, Keiser & Ravin,1990, 75). The ultimate goal of parental education for the parents of a new-born child with a cleft is to maintain or increase the fuctional level of the parents. The parents should adapt themselves in a constructive way by being active, not in a resigned way, responding by passivity. The activity does not nesessarily mean that the parents should be active outside the home, engaged in hobbies or voluntary work. But they should be active and responding in their relation to their child and his needs - and in relation to each other and themselves. At an early stage, the activity might mean the capability to seek help.

Ferguson & Ferguson (1987) distinguishes between different types of parental involvement programs. They use these types to describe parental involvement in special education programs for their children, but their model may also be used to describe different approaches to parental education.

The dimensions of parental involvement are the *type* of involvement (active or passive) and the *extention* (narrow - broad). A passive and narrow parental involvement is the psychoanalytical *parent counselling* that focuses on individual emotional support (therapy). A passive and broad approach is *parent support* *groups*. This orientation is psychosocial. The functionalist approach has led to *parent training* programs (active and narrow), while the interactionist orientation is *parent empowerment* (active and broad). It is, however, important to point out that a successful parent support group, even if it has a passive approach (with the parents "receiving" information), can result in very active parents with a high level of functioning

Using the results from this study, two different objectives for parental education for parents of children with cleft lip and/or palate were formulated:

1. To increase knowledge about the cleft problem and skills in how to take care of the baby during the first year.
2. To provide the possibility for contact and a sense of community

Information

Since the information given at the hospitals was considered poor, the first task was to increase the information at the hospitals. That has been done in cooporation with the researcher and the Cleft Palate Center, Helsinki University Central Hospital. A booklet about how to feed a new-born with a cleft has been distributed to all hospitals (in Finland) with a delivery ward. A videotape has also been produced for the same purpose; by now it is available to all families with a newborn child with a cleft. The main information focuses on the following subjects:

1. A presentation of the cleft lip and/or palate problem
2. A presentation of the surgeries with before-after pictures
3. Feeding an infant with a cleft
4. Hearing and speech

The first information is presented in a positive way, to give the parents hope for the future, to reduce feelings of guilt by telling the parents that the cleft is not their fault and trying to normalize the situation by focusing on the child as a whole. The parents are also provided with information regarding contact numbers for help, and they are informed about the Finnish Cleft Palate Association.

The Central Union for Child Welfare in Finland has reinstated an "Initial Information Project", focusing on educating the personnel at hospitals with delivery wards in how to handle the situation when a new-born baby is malformed, handicapped or sick (Niklander 1993). The emphasis here is to provide the parents with hope for the future. The education of the personnel at the hospitals, combined with an information package about cleft, should give parents a better start in the future than that by those parents who took part in this study.

How well the information reaches the families will also be evaluated in a study carried out by the Cleft Palate Center, Helsinki University Central Hospital. The researcher has been used as a consultant in planning this evaluation project.

Contact and Sense of Community

The importance of contact and sense of community in educative processes has been pointed out by such theorists as Freire (1972), Rogers (1976) and Dewey(1980). In order to give the parents a possibility, not only to get more information, but to share experiences with each other as well, the researcher has planned and participated as a lecturer in so-called adaptation courses for families with children with a cleft lip and/or palate (these courses are close to the parent support group idea described above). The first course was held in May 1992, and a total of three courses are planned to be held each year (for a total of about 21 families). These courses have not been evaluated for research purposes, but they have been highly appreciated by the families involved. Dewey's idea that "the process is the goal " (Dewey 1980) may be applied to such courses.

These adaptation courses have focused on information about how to take care of a child with a cleft - for some families one goal has been to learn to feed the baby. The families also get information about surgery and about being in a hospital with the baby. The speech-patologist talks about communication and speech-development, and the families also get information about respiratory-infections and dental problems. In addition, the families receive information about genetics, and they may also have a person-to-person meeting with a surgeon. The daily groupsessions with a family therapist provide the families with a possibility to express their feelings and to work on them.

The findings from this study have also been used in the discussions, especially the crisis-definition, "the child in the mirror" and "the loving-more dimension". A lot of families have expressed that this was the first time they felt that they were "allowed" to have negative feelings, and they were "allowed" to have difficulties, for exemple, going shopping with the baby.

The idea of offering a possibility for contact and a sense of community also touches upon the idea of "welfare" introduced by Erik Allardt (1971): Welfare, in addition to "having", also means "loving" and "being", or in other words closeness, togetherness, belongingness and self-actualization. "Loving" and "being" should not be preserved for a higher level of subjective welfare, which might go beyond all public social politics. On the contrary: "loving" and "being" have a real basis in social relationship, patterns of access and competence, which can be measured and shaped politically. They are an important part of human resources (Zapf 1993, 14, 15). By offering possibilities for a constructive adaptation for "special parents", we do not only add to the quality of life of these families now, but we also prevent problems in the future.

6. CONCLUDING REMARKS

This study focused on psychosocial aspects of clefting and on their implications for parental education. The main emphasis was on how the cleft problem influences the bonding process between a mother and her child. At the outset three questions were formulated, and all these questions were related to the tension between the *noema* and the *noesis* of cleft: that is, the relation between the "real cleft" and how the mother experienced it, the relation between the "what" and the "how". The questions formulated in the beginning of the study were:

1. Is the mother's experience of the cleft of her child directly proportional with the severity of the cleft? or
2. Is the mother's experience of the cleft associated with the *apprehension* of the severity of the cleft problem she felt when the baby was born? and
3. Which of the typical problems connected with the cleft, the visual and the functional problem, is apprehended as more difficult to accept by the mothers?

The answer to these questions were formulated in Chapter 4: in this study, a defect that interfered with feeding was more difficult to cope with than a defect that interfered only with appearence. In a "crucial test" between the impact of a visual defect and a functional defect, the functional defect seems to have a greater impact on early maternal-infant bonding.

In addition to this, it seems to be very important to provide correct information about the problem quickly at the time of the birth. However, the mothers' experience of the cleft is not directly proportional with the (clinical) severity of the cleft, since a baby born with a small cleft in the soft palate can be a severe disappointment to the mother. This disappointment can be connected with the apprehension the mother feels regarding the severity of the problem, but it may also be connected with several other factors, such as the personality of the mother and her previous experiences, over which the personnel in the delivery ward has little control.

So, even if the question of what is "real" is a matter of social definition (Ferguson et al. 1992, 5) (in this study the cultural life-world of the mothers), there seems to be a stable part concerning the cleft palate problem: the feeding problem. However, both the cultural life-world and the more stable part, to a certain extent, may be affected by intervention.

Therefore, the recommendation was that the most important thing for the personnel of the delivery ward is to support the parents and facilitate the bonding process between the parents and the child. In addition, it is very important to offer a possibility for the family to attend adaptation courses were they may receive more information about the cleft palate problem and also may have a possibility to express their feelings and to work on them.

At this point, however, it is important to probe the results and the method that was used in this study.

Phenomenology, Phenomenological Method and Its Value for Studying the Cleft Palate Problem

The method used in this study is vulnerable to criticism for many reasons. The first objection may be posed regarding the phenomenological approach itself and the worldview it has as its standpoint. The second objection may be posed of the bridge between phenomenology as a philosophy and the phenomenological method. And finally, objections may be made against the way the phenomenological method has been used in this study and its value for studying the cleft palate problem.

The phenomenological approach emphasizes the importance of the unique interpretations and the unique life-worlds different individuals have. This approach urges us to ask different questions, and also to ask questions differently. Phenomenology is the study of essences, but also a study of existence and meaning. Today, the importance of the unique interpretations of individuals, when trying to reach a deeper understanding of a phenomenon is widely accepted. Qualitative research, interpretivism, ethnography, hermeneutics are all terms for different ways of gathering information about the world that share much of the worldview of phenomenology. Thus, the objection to the method used in this study is more likely to be the bridge between phenomenology as a philosophy and the phenomenological method as used to study the cleft palate problem.

The phenomenological method was used following four steps: bracketing, describing, horizontalization and finding invariant features of the phenomena. The first three steps belonged to the stage of negative reduction, and the fourth belonged to the positive reduction. When studying different theorists, it appears that they reach a fairly good consensus regarding the matter of the characteristics of the phenomenological method (see Natanson 1973; Stewart & Mickunas 1974; Spiegelberg 1982; Giorgi 1985; Ihde 1986; Spinelli 1989; Karlsson 1993). In short, a method may be considered phenomenological if it is based on reduction, is descriptive, seeks for essences, and presupposes intentionality (Giorgi 1985a). If we accept this definition, the method used in this study may be considered phenomenological.

On a more general level, in order for an activity to be considered scientific, it should be able to be performed by other researchers, the findings should be intersubjectively valid and there must be a definable method (Giorgi 1985b, 72). The qualitative researcher also has an obligation to be methodical in reporting sufficient details of the data-collection and the analysis, to permit others to judge the qualtity of the resulting product (Patton 1990, 463). In this study, details of the data-collection have been reported through quotations and through the data matrix in Appendix. Different techniques were used in analyzing the material (tables, crosstab tables and tables showing the development of bonding patterns, in Chapter 4). Therefore, readers of this study should be able to make their own decisions about the plausibility of the explanations and findings.

But even if the phenomenological method as used in this study is accepted, the results may be questioned. The impact of the researcher is especially relevant in qualitative studies, because the researcher is the instrument of the data collection and the center of the analytic process. The researcher is the one who understands and interprets the results. Therefore, in order to probe the results, it is important to go back to the relation between understanding and interpretation in research.

Understanding and Interpretation

What is the relation between understanding and interpretation? Hermeneutics has been described as the science of interpretation, while phenomenology emphasizes understanding. Originally, hermeneutics arose as a pedagogical aid in exceptional cases where our understanding of what a text says is blocked for some reason (Linge 1977, xiii). Beginning with Schleiermacher, what a text "really" means is not what it seems to tell us directly: only a critical and methodologically-controlled interpretation can reveal the author's meaning to us. The source of prejudices and distortions that block valid understanding, according to Schleiermacher (and also to Dilthey), is precisely what the interpreter must transcend to avoid misunderstandings. Schleiermacher and Dilthey are trying to interpret a meaning that lies behind the text, a meaning that is not explicit.

However, interpretation may be fruitful, but it may also be unfruitful. If, for example, we apply hermeneutics to provide us with a crisis theory that we may "believe in", there is a risk that we try to fit the mothers (in this study) into the theory, and if they do not fit, the worse for the mothers. In this case, the famous hermeneutic circle becomes a *circulos victious*. We have interpretation, but we lack understanding.

Hermeneutics before Gadamer may be described as a method to build a bridge between the researcher and the object of research, to reconstruct meaning. (Gadamer 1977a, 8.) For Gadamer, the understanding is not reconstruction, but a transmission of meaning, the "fusion of two horizons" (Linge 1977, xix). Avoiding misunderstandings, according to Gadamer, may therefore not be the first task of hermeneutics. The case is quite the reverse. The transmission of meaning may occur in a genuine dialogue where both conversational partners are concerned with a common subject matter. Thus, the understanding comes first, because only the support of familiar and common understanding makes possible venturing into the alien. (Gadamer 1977a, 15.)

In this study, the relation between understanding and interpretation is the following: as long as we understand, we do not have to interpret. Interpretation takes place when we lack familiar and common understanding. This may be the case when the researcher lacks knowledge by acquaintance of the problem, when he is trying to achieve understanding through "controlled alienation" (through the methodological development of intelligence) (Gadamer 1977a, 27). This does not imply that interpretation is always wrong: it only implies the importance of timing. If we start to make interpretations too soon, they might lead us in the wrong direction, and result in "alienated understanding". Before we can interpret, we must understand. Then the next question must be: how do we know if our understanding is correct? Phenomenology has tried to give an answer to this question. This answer begins with the question about the nature of our knowledge.

The Way to Find the Eidos

Husserl's standpoint is radical: it is pure nonsense to try to clairify a problem by logical reasoning from a non-intuitive knowledge, based on scientific conclusions (transcendent knowledge). Take for example the man that is born deaf: he can never understand music, even if he knows that music exists. To deduce from existing things that we have knowledge about, but cannot behold, is, according to Husserl, not possible (Husserl 1989, 79). His standpoint is that we have to have immanent knowledge. This standpoint is the same as that of Gadamer. To have knowledge by acquaintance is then not a weakness, but a condition for the capability of a person to understand a problem. This is the first condition.

So now we know the basis: immanent knowledge. Without that, we do not even have a possiblity to understand. But this is not enough. The question remains: how do I know that my understanding of a phenomenon is correct? The next step comes as a paradox: now that we have this understanding, we have to bracket it, going through the steps that have been described in the first chapter, the epoché. By negative reduction we will be able to go "back to the things themselves", and by positive reduction (eidetic reduction) we will be able to find the *eidos* of the phenomenon we study.

But even if we can accept epoché as a way to find the eidos of a phenomenon, we still have to question the result of the epoché. Is there really only one eidos of a phenomenon, or are there several different eidos? And if there are several, how do we now if the eidos we found is the relevant one? According to Juntunen, the answer is clear: there are several relevant eidos for one phenomenon - in fact Juntunen talks about several parallel hierarchies of eidos (Juntunen 1986, 77) - and it is the *interest of knowledge* that .determines which eidos is relevant in one situation, and which is relevant in another. This interest of knowledge may be compared to the same concept that Habermas (1971) uses, but in this case it refers to the *intentionality* the researcher has, the directional shape of attention. Thus there is no "correct understanding" for a phenomenon, only a possibility to find (situationally-bounded) relevant aspects of it.

In this study, the phenomenon that was studied was the cleft lip and/or palate problem. The result was that a problem that interfered with feeding was considered as having more impact on early bonding than a problem that only interfered with appearance. Does this then mean that the relevant eidos of a cleft lip and palate is a functional problem? The answer is no. The cleft lip and palate problem has two eidos: the visual and the functional. These eidos belong to two different and parallel hierarchies:

EIDOS A	EIDOS B
Severe visual defect	Severe functional problems
Medium visual defect	Medium functional problems
Small visual defect	Small functional problems
None visual defect	No functional problems

The importance of these two eidos vary over time. In the beginning, during the first year, the functional problems are connected with eating and feeding. What the result says is that a functional problem is more severe than a small visual defect in the beginning, during the first months of the child's life. Also, this result may be a matter of social definition, and bounded to the cultural life-world of the mothers. The result may also be a matter of the interest of knowledge, and bounded to the aims of the researcher. On the other hand, it may also be a result that is applicable on a more general level. In Chapter 4 it was suggested that the results in this study can be interpreted so that a visual defect disturbs the bonding process mechanically (the baby looks different), while the functional defect disturbs the bonding process in a dynamical way (the baby acts differently and this disturbs the interaction between the baby and his mother). There is also a growing interest in how different feeding patterns affect not only bonding and attachment issues, but also the emotional and cognitive development of the child (several presentations on these issues were scheduled to take place at the World Infant Mental Health Congress in Riga in June 1994).

But let us examine a little bit closer the two eidos found in this study. These two hierarchies of eidos may be combined in several different ways. First, the combination of no visual defect and no functional problems is the case of the "normal" (non-cleft) child. The combination of a small visual defect and no functional problems may be the case of the "normalized" child (with a small cleft lip): the mother adapts herself quickly to the situation (case number two in Chapter 2 is a good example of this). The combination of a visual defect and a functional problem is the case with the "defective" child: the defect cannot be hidden, and it gets attention both from the mother and the environment. Hence relatives and friends can understand the problems the mother has with feeding the baby, and offer her some help (case number three in Chapter 3).

The combination of no visual defect but functional problems has many different solutions: in some cases, and according to this study especially if the functional problems are very small (for example when the mother is able to breast-feed the baby), the mother decides that her child is normal, even if he has a cleft, and the case is "normalized". In other cases, the mother decides that the child has a defect, and she tells her relatives and friends, which helps them to understand her problems with feeding the baby.

In a few cases, the mother decides that her child is defective (which is quite different from the decision that the child has a defect) and she decides to hide the fact. In this case the child might become "pathologized", because the mother constantly seeks other problems that the child might have, and in addition, she has to bear the whole burden by herself: nobody understands her problems or gives her support (case number one in Chapter 2 is an example of this). This "pathologizing" can also happen with other types of clefts, but when the child has a visual cleft, the cleft cannot be hidden. However, the parent may try to hide the child. This problem was discussed in chapter 5 (The Child in the Mirror).

In this light it is possible to understand why a less dramatic defect, such as a small cleft in the soft palate, in some cases may be more difficult for the mother to accept than a more dramatic defect, such as a cleft lip and palate. This was also noted in Spriestersbachs (1973) study on the parents of 140 children with clefts. Let us therefore examine his conclusion again: "The one exception to this pattern (that the visual cleft is more problematic) is the frequency of mothers of children with cleft palate only with being overwhelmed by the problem. Although these children have no cosmetic problem, they frequently do have other conditions which are prejudicial to survival. particularly the feeding problem "(Spriestersbach 1973, 63). And: "In this case (the case of the cleft palate only) the parents are frequently led to believe that they have indeed been fortunate and that shortly, when the palate is closed, all will be well. Yet the parents of a child with a cleft of the palate only tend to perceive him less favorably than do the parents of a child with a cleft lip and palate" (Spriestersbach 1973, 158).

Spriestersbach offers no explanations for his findings. One possible explanation is offered in this study. If we believe that early bonding and attachment processes have an impact on the development of a child, the results in this study are significant.

Feeding is here seen as one aspect of communication between the mother and the child. Since there is some evidence that other aspects of communication patterns might also be disturbed when the child has a cleft, the next focus of interest is on early communication patterns between mothers or primary caretakers and their infants. It is of special interest to see if problems with early communication correlate with communication, articulation and learning problems for the child in the future, and if these problems can be prevented or diminshed by early intervention (such as helping the parents to develop more nuturant communication patterns).

A follow-up study with the children in this study is one possibility to see if problems with feeding in the beginning correlate with later communication problems for the child. As the children are tested by a phonetician when they are 3 years old, this can easily be done. Another project will be to study early communication patterns by videotaping a test group (mothers and infants with a cleft) and a matched control group (mothers and non-cleft infants).

It is my personal hope that this study has contributed to a deeper understanding of the problems a family might face when a child with a cleft is born and of how the families may be helped to overcome these problems. The study will be continued along the lines described above.

REFERENCES

Ainsworth, M. S. 1990. Some Consideration Regarding Theory and Assessment Relevant to Attachments Beyond Infancy. In Greenberg, M., Cicchetti, D. & Cummings, M. (eds.) Attachment in the Preschool Years. Chicago: The University of Chicago Press, 463 - 488.

Alasuutari, P. 1993. Laadullinen tutkimus. (Qualitative Research) Tampere: Vastapaino.

Alberoni, F. 1979. Förälskelse och kärlek. (Innamoramente e amore) Uddevalla: Bokförlaget Korpen.

Allardt, E. 1971. About Dimensions of Welfare. Research Group for Comparative Sociology. Research Reports 1. Univeristy of Helsinki.

Alvesson, M. 1989. Sociala störningar av självet. (Social Disturbances of Self) Lund: Studentlitteratur.

Andersson, S. 1982. Positivism kontra hermeneutik. (Positivism and Hermeneutics) Göteborg: Bokförlaget Korpen.

Antohny, E. J. & Koupernik, C. 1970. The Child in His Family. The International Yearbook for Child Psychiatry and Allied Disciplines 1. New York: Wiley - Interscience.

Atkinson, R., Lindzey, G. & Thompson, R. 1984. Social Stigma: The Psychology of Marked Relationships. New York: W.H. Freeman & Co.

Baldwin, A. L. 1967. Theories of Child Development. New York: Wiley International Edition.

Bardach, J. & Morris, H. L. 1990. Multidisciplinary Management of Cleft Lip and Palate. Philadelphia:W.B. Saunders Company.

Belfer, M. L., Harrison A. M., Pillemer, F. C. & Murray J. E. 1982. Appearance and the Influence of Reconstructive Surgery on Body Image. Clinics In Plastic Surgery 9 (3). Philadelphia: WB Saunder Company, 305 - 312.

Bettelheim, B. 1970. Äidit, lapset, ongelmat. (Dialoges with Mothers) Helsinki: Otava.

Bettelheim, B. 1989. Att duga som förälder: En bok om barnuppfostran. (A Good Enough Parent: A Book on Childrearing) Norstedts. Finland: WSOY.

Bowlby, J. & Parkes, C. M. 1970. Separation and Loss Within the Family. In Antohny, E. J. & Koupernik, C. (eds.) The Child in His Family. The International Yearbook for Child Psychiatry and Allied Disciplines 1. New York: Wiley - Interscience, 197 - 216.

Bowlby, J. 1988. A Secure Base. Clinical Applications of Attachment Theory. London: Routledge.

Brazelton, T. B. & Als, H. 1979. Four Early Stages in the Development of Mother-Infant Interaction. Psychoanalytic study of the Child 34, 349 - 369.

Bretherton, I., Biringen, Z. & Ridgeway, D. 1991. The Parental Side of Attachment. In Pillemer, K. & McCartney, K. (eds.). Parent-Child Relationships Throughout Life. Hillsdale, New Jersey: Lawrence Erlbaum Associates, 1 - 24.

Bronfenbrenner, U. 1975. Is Early Intervention Effective? In Bronfenbrenner, U. & Mahoney, M. A. (eds.) 1975. Influences on Human Development. Second Edition. Hinsdale: The Dryden Press, 329 - 354.

Bronfenbrenner, U. 1979. The Ecology of Human Development: Experiments by Nature and Design. Massachusetts: Harvard University press.

Bronfenbrenner, U. 1981. Sosialisaatiotutkimus. (Ökologische Sozialisationsforschung) Transl. by Pirkko Ikonen. Espoo: Weilin+Göös.

Bronfenbrenner, U. & Mahoney, M. A. (eds.) 1975. Influences on Human Development. Second Edition. Hinsdale: The Dryden Press

Bruch, H. 1970. Family Background in Eating Disorders. In Antohny, E. J. & Koupernik, C. (eds.). The Child in His Family. The International Yearbook for Child Psychiatry and Allied Disciplines. 1. New York: Wiley - Interscience, 285 - 310.

Bäckman, G. 1993. Psykosociala faktorer och hälsa. (Psychosocial Elements and Health) In Granfelt, R., Jakobson, G., Ljungberg, J., Siiriäinen, I., Suominen, S., & Törrönen, M. (eds.). Framtiden i nuet. Helsinki: Yliopistopaino, 56 - 61.

Chamberlin, J. G. 1974. Phenomenological Methodology and Understanding Education. In Denton, David. (ed.). Existentialism & Phenomenology in Education: Collected Essays. New York: Teachers College Press, Columbia University, 119 - 138.

Chapman, K. & Hardin, M. 1991. Language input of mothers interacting with their young children with cleft lip and palate. Cleft Palate - Craniofacial Journal 28 (1), 78 -85.

Charrow, J. 1990. Genetics of Cleft Lip and Palate. In Kernahan, D. & Rosenstein, S.W. (eds.). Cleft Lip and Palate: A System of Management. Baltimore: Williams & Wilkins, 21 - 27.

Chase, L., Stan, D., Tvedte, C. & Wagner, B. 1990. Comprehensive Nursing Care for Cleft Patients. From Bardach, J. & Morris, H. L. (eds.). Multidisciplinary Management of Cleft Lip and Palate Philadelphia: W.B. Saunders Company, 30 - 36.

Cherniss, D. S., Pawl, J. & Fraiberg, S. 1990. Nina: Utvecklingsvägledning och stöd för ett spädbarn som inte växer och hennes tonårsmor. In Fraiberg, S.(ed.). Det första levnadsåret. Om spädbarns psykiska hälsa.(Origin. Clinical Studies in Infant Mental Health: The First Year of Life) Stockholm: Natur och Kultur, 118 - 158.

Child Welfare 1987, 1991. 1993. National Research and Development Centre for Welfare and Health (STAKES). Jyväskylä: Gummerus

Cicchetti, D. & Carlsson, V. (eds.) 1990. Child Maltreatment: Theory and Research on the Causes and Consequences of Child Abuse and Neglect. New York: Cambridge University Press.

Clements, I. W. & Robert, F. B. 1983. Family Health. A theoretical approach to Nursing Care. New York: John Wiley & Sons.

Collier, A. 1977. R.D. Laing: the Philosophy and Politics of Psychoterapy. Sussex: The Harvester Press.

Cooley, C. H. 1964. Human Nature and the Social Order. New York: Schocken.

Coser, L. A. 1977 Masters of Sociological Thought: Ideas in Historical and Sociological Context. New York: Harcourt Brace Jovanovich International Edition.

Crittenden, P. & Ainsworth, M. D. S. 1990. Child maltreatment and attachment theory. In Cicchetti, D. & Carlsson, V. (eds). 1990. Child Maltreatment. Theory and Research on the Causes and Consequenses of Child Abuse and Neglect. New York: Cambridge University Press, 427 - 436.

Cullberg, J. 1979. Kris och utveckling. (Crisis and Development) Stockholm: Natur och Kultur.

Cummings, E. M. 1990. Classification of Attachment on a Continuum of Felt Security: Illustrations from the Study of Children of Depressed Parents. In Greenberg, M., Cicchetti, D. & Cummings, M. 1990. Attachment in the Preschool Years. Chicago· The University of Chicago Press, 311 - 339.

Curtis, B. 1978. Foreword. In Curtis, B. & Mays, W. (eds.) 1978. Phenomenology and Education. London: Methuen.

Curtis, B. & Mays, W. (eds.) 1978. Phenomenology and Education. London: Methuen.

Dahlin, O. 1983. Foreworld to Winnicott, D.C. Barnet, familjen och omvärlden. (The child, the family and the outside world) Stockholm: Natur och Kultur.

D'Arcy, E. 1968. Congenital Defects: Mothers' reactions to First Information. Brittish Medical Journal 3, 796 - 798.

Davis, M. & Wallbridge, D. 1984. Äidin ja lapsen mysteeri. Winnicottin psykoanalyyttinen ajattelu. Transl. by Stig Hägglund and Leena Ketola. Espoo: Weilin + Göös.

Davis, T. A. 1990. Pediatric management of the Child with a cleft. In Kernahan, D A. & Rosenstein, S. W. 1990. Cleft Lip and Palate: A System of management. Baltimore: Williams & Wilkins, 28 - 32.

Denton, D. (ed.) 1974. Existentialism & Phenomenology in Education. Collected Essays. New York: Teachers College Press, Columbia University.

Dewey, J. 1980. Individ, skola och samhälle. (School and Society) Stockholm: Natur och Kultur.

Dunn, J. 1991. The Developmental importance of Differences in Siblings' Experiences Within the Family. In Pillemer, K. & McCartney, K. (ed.) Parent-Child Relationships Throughout Life. Hillsdale, New Jersey: Lawrence Erlbaum Associates, 113 - 124.

Edfeldt, Å. 1976. Reflektioner kring fenomenologi och fenomenologisk metod. (Reflections About Phenomenology and Phenomenological Method) Forskningsrapport från Pedagogiska institutionen, Stockholms Universitet, 4.

Eliason, M.J. 1990. Neuropsychological perspective of Cleft Lip and Palate. From: Bardach, J. & Morris, H. L. Multidisciplinary Management of Cleft Lip and Palate. Philadelphia: W. B. Saunders Company, 825 - 834.

Elkind, D. & Weiner, I. B. 1978. Development of the Child. New York: John Wiley & Sons, INC.

Engdal, H., Holmgren, O., Lysell, R., Melberg, A. & Olsson, A. (eds.).1977. Hermeneutik. (Hermeneutics.) Stockholm: Rabén & Sjögren.

Erikson, E. H. 1965. Childhood and Society. Rev. Ed Harmonnworth: Penguin Book.

Erikson, E. H. 1985. Den fullbordade livscykeln (The Life Cycle Completed) Lund: Natur och Kultur.

Farina, A. 1984. The Dimensions of Stigma. In Jones, E, & Farina, A. & Hastorf, A., Markus, H. Miller, D. Scott, R.1984. Social Stigma. The Psychology of Marked Relationships. New York: W H. Freeman and Company, 24 - 80.

Feldman, W. 1980. Sairaalapsykologia. (Psychology for hospitals) Transl. by Mirja Rutanen. Juva: WSOY.

Felix-Schollaart, B. 1989. Solitary, Non-Syndromic Cleft Lip and/or Palate. Amsterdam: Vrije Universitet. Subfacultet der tandheelkunde. Academisch Proefschrift.

Ferguson P. M. & Ferguson D. L. 1987. Parents and Professionals. In Knoblock, P. (ed.) Understanding Exceptional Children and Youth. Boston: Little, Brown & Co., 346 - 388.

Ferguson P. M., Ferguson D. L. & Taylor, S. J. 1992. Introduction: Interpretivism and Disability Studies. In Ferguson P. M., Ferguson D. L. & Taylor, S. J. Interpreting Disability: A Qualitative Reader. New York: Teachers College Press, 1 - 18.

Field T.M. & Vega-Lahr N. 1984. Early Interactions Between Infants with Craniofacial Anomalies and Their Mothers. Infant Behavior Development 7, 527 - 530.

Fraiberg, S. 1990. Det första levnadsåret: Om spädbarns psykiska hälsa. (Clinical Studies in Infant Mental Health: The First Year of Life) Stockholm: Natur och Kultur.

Frankl, V. E. 1986. Viljan till mening. Logoterapins grunder och tillämpning. (The Will to Meaning) Lund: Natur och Kultur.

Frankl, V. E. 1990. Psykiatern och själen. Logoterapins och existensanalysens grunder. (Ärtzliche Seelsorge.) Borås: Natur och Kultur.

Freedle, R. & Lewis, M. 1977. Prelinguistic conversations. In Lewis, M. & Rosenblum, M (eds.) Interaction, Conversation and the Development of Language. The Origins of Behavior Series, vol 5. New York: John Wiley & Sons, 175 - 185.

Freire, P. 1972. Pedagogik för förtryckta. (Pedagogy of the Oppressed) Stockholm: Gummessons.

Furneaux, B. 1988 Special Parents. Philadelphia: Open University Press.

Gadamer, H-G. 1977a. Philosophical hermeneutics. Los Angeles: University of California Press.

Gadamer, H-G. 1977b. Tidsavstånd, verkningshistoria och tillämpning i hermeneutiken. (Time Distance, History of Effects and Applications in Hermeneutics.) In Engdal, H., Holmgren, O. Lysell, R., Melberg, A., Olsson, A. (eds.) Hermeneutik (Hermeneutics) Stockholm: Rabén & Sjögren, 88 - 109.

Glaser, B. G. 1978. Theoretical Sensitivity: Advances in the Methodology of Grounded Theory. Mill Valley: The Sociology Press.

Glaser, B. G. & Strauss, A. L. 1967. The Discovery of Grounded Theory: Strategies for Qualitative Research. New York: Aldine Publishing Company.

Giddens, A. 1976. New Rules of Sociological Method: A Positive Critique of Interpretative Sociologies. London: Hutchinson.

Giddens, A. 1984. The Constitution of Society. Cambridge: Polity Press.

Giorgi, A. (ed.) 1985. Phenomenology and Psychological Research. Pittsburg: Duquesne University Press.

Giorgi, A. 1985a. Sketch of a Psychological Phenomenological Method. In Giorgi, A. (ed.) Phenomenology and Psychological Research. Pittsburg: Duquesne University Press, 8 - 24.

Giorgi, A. 1985b. The Phenomenological Psychology of Learning and the Verbal Learning Tradition. In Giorgi, A. (ed.) Phenomenology and Psychological Research. Pittsburg: Duquesne University Press, 25 - 85.

Goffman, E. 1968. Stigma: Notes on the Management of Spoiled Identity. London: Penguin Books Ltd.

Goldberg, R. B. 1990. Genetic Counseling of Cleft Lip and Palate. In Bardach, J. & Morris, H. L. Multidisciplinary Management of Cleft Lip and Palate. Philadelphia W.B. Saunders Company, 120 - 128.

Gummeson, E. 1988. Qualitative Methods in Management Research. Lund: Studentlitteratur. Chartwell Bratt.

Gustavsson, A. 1989. Samhällsideal och föräldraansvar: Om föräldrar till förståndshandikappade barn. (Ideals of the Society and Responsibility of the Parents: About Parents of Mentally Handicapped Children) Stockholm: Almqvist & Wiksell.

Greenberg, M., Cicchetti, D. & Cummings, M. 1990. Attachment in the Preschool Years. Chicago: The University of Chicago Press.

Grene, M. 1969. Knowing and Being. Essays by Michael Polanyi. Chicago: The University of Chicago Press, 159 - 180.

Haapanen, M.-L. 1992. Factors Affecting Speech in Patients with Isolated Cleft Palate: A methodic, clinical and instrumental study. Helsinki: Cleft Center, Department of Plastic surgery, University of Helsinki.

Haapanen, M.-L. 1993. Honottava lapsi. (Hypernasality in Children.) In Iivonen, A. & Lieko, A & Korpilahti, P. (eds.) Lapsen normaali ja poikkeava kielen kehitys. (Normal and Deviant Development of Speech.) Helsinki: Suomalaisen kirjallisuuden seura.

Habermas, J. 1971. Theorie und Praxis. Sozialphilosophische Studien. Berlin: Suhrkamp

Habermas, J. 1984. Den rationella övertygelsen. En antologi om legitimitet, kris o politik. (Legitimacy and Crisis) Stockholm: Akademilitteratur.

Hansen, S. 1992. Människobarn och djurungar. (Human Infants and Animal Newborns) In Hwang, P. (ed.). Barnets tidiga relationer. (Early Relations of the Infant) Second Edition. Lund: Natur och Kultur, 13 - 32.

Harman, D. & Brim, O. 1980. Learning to be parents: Principles, Programs and Methods. Beverly Hills: SAGE publications.

Hautamäki, A. 1993. Down-lapsi perhe-elämän kaaressa. (The Down-child in the Life-cycle of the Family.) Valtakunnallisen tutkimus- ja kokeiluyksikön julkaisuja 62. Helsinki: Kehitysvammaliitto.

Heidegger, M. 1962. Being and Time. (Sein und Zeit) New York: Harper & Row.

Hellsten, K. 1992. Muuttuva yhteiskunta ja sosiaalipolitiikan keskeiset arvot ja päämäärät. (The Changing Society and the Central Values and Goals of Social Politics) In Riihinen, O. (ed.) Sosiaalipolitiikka 2017: Näkökulmia suomalaisen yhteiskunnan kehitykseen ja tulevaisuuteen. (Social Politics 2017: On the Development and Future of the Finnish Society) Juva: WSOY

Henderson, R. W. (ed.) 1981. Parent - Child Interaction: Theory, Research and Prospects. New York: Academic Press.

Hillgaard, L., Keiser, L. & Ravin, L. 1990. Sorg och kris. (Mourning and Crisis) Borås: Liber.

Husserl, E. 1989. Fenomenologins idé. (Die Idee der Phänomenologie) Uddevalla: Daidalos.

Hwang, P. (ed.). 1992. Barnets tidiga relationer. (Early Relations of the Infant) Borås: Natur och Kultur.

Igra, L. 1987. Objektrelationer och psykoterapi. (Object-relations and Psychoterapy) Lund: Natur och kultur.

Ihde, D. 1986. Experimental Phenomenology. An introduction. Reprint. New York: State University of New York Press.

Iivonen, A. & Lieko, A. & Korpilahti, P. (eds.) 1993. Lapsen normaali ja poikkeava kielen kehitys. (Normal and Deviant Development of Language) Helsinki: Suomalaisen kirjallisuuden seura.

Ijizerndoorn, M. H. van & Tavecchio, L. W. C. & Goosens, F. A. & Vergeer, M. M. 1982. Opvoeden in geborenheid: een kritische analyse van Bowlby's attachmenttheorie. Van Loghum Saterns, Deventer. Referred to in Singer, E. 1992. Child-care and the Psychology of Development. London: Routledge.

Ijäs, K. 1984. Perhe - ihmissuhteen kypsyyskoe. (Family - the Maturity-test of Human Relation) Jyväskylä: Kirjapaja.

Irvin, N. A., Kennell, J. H. & Klaus, M. H 1976. Caring for Parents of an Infant with a Congenital Malformation. In Klaus, M. H. & Kennell J. H. Maternal Infant Bonding. The Impact of Early Separation and Loss on Family Development. Saint Louis: The C.V. Mosby Company, 167 - 208.

Jeffmar, C. 1983. Modern utvecklingsspykologi från foster till vuxen människa. (Modern Development Psychology from Fetus to Adult.) Lund: Studentlitteratur.

Jones, B. W. 1988. Weight-Gain and Feeding in the Neonate With Cleft: A Three-Center Study. Cleft Palate Journal 25 (4), 379 - 384.

Jones, E., Farina, A., Hastorf, A., Markus, H. Miller, D. & Scott, R.1984. Social Stigma. The Psychology of Marked Relationships. New York: W.H. Freeman and Company.

Juntunen, M. 1986. Edmund Husserlin filosofia. (The Philosophy of Edmund Husserl) Mänttä: Gaudeamus.

Kapp-Simon, K., Simon, D., & Kristovich, S. 1992. Self-Perception, Social Skills, Adjustment, and Inhibition in Young Adolescents with Craniofacial Anomalies. Cleft Palate-Craniofacial Journal 29 (4), 352 - 356.

Karlsson, G. 1993. Psychological Qualitative Research for a Phenomenological Perspective. Stockholm: Almqvist & Wiksell International.

Kempe, R. S. & Kempe, C. H. 1981. Lasten pahoinpitely. (Child Abuse) Transl. by Oili Aho. Helsinki: Lastensuojelun keskusliiton julkaisuja 63.

Kernahan, D. A. & Rosenstein, S. W. (eds.) 1990. Cleft Lip and Palate: A System of Management. Baltimore: Williams & Wilkins.

Klaus, M. H. & Kennell J. H. 1976. Maternal Infant Bonding. The Impact of Early Separation and Loss on Family Development. Saint Louis: The C. V. Mosby Company.

Koopmans-van Beinum, F. J., van der Stelt, J. M. & Jansonius-Schultheiss, K. 1988. The Development of Speech Communication in Normal and Cleft Palate Babies: State of the Art of a Project. Proceedings 12. Amsterdam: Institute of Phonetic Sciences. University of Amsterdam.

Kristiansen, I. 1992. Nonverbal intelligence and Foreign Language Learning. Research Bulletin 73. University of Helsinki. Department of Education. Helsinki: Yliopistopaino.

Kvale, S. 1989. Issues of Validity in Qualitative Research. Lund: Studentlitteratur.

Lagerberg, D. 1983. Föräldrautbildning - för vem? Om utvärdering av föräldragrupper. (Parental Education - for whom? On Evaluation of Parental Groups) Stockholm: LIBER.

Lahelma, E. 1993, June. The Patterning of Responses to Unemployment: Deprivation and Adaptation Paper presented at the international meeting: The effects of Economic Changes on Social Welfare and Health, Finland.

Laing, R. D., Phillipson, H & Lee, A. R. 1972. Interpersonal perception: A theory and Method of Research. New York: Tavistock Publications, Springer Publishing Company.

Lavigne, J. V. & Wills, K. E. 1990. Psychological Aspects of Clefting. In Kernahan & Rosenstein, Sheldon W. Cleft Lip and Palate. A System of Management. Baltimore: Williams & Wilkins, 37 - 46.

Lebovici, S. 1970. The Psychoanalytic Theory of the Family. In Antohny, E. J. & Koupernik, C. The Child in His Family. The International Yearbook for Child Psychiatry and Allied Disciplines1. New York: Wiley - Interscience, 1 - 18.

Leonard, B., Burst, J., Abrahams, G. & Sielaff, B. 1991. Self-Concepts of Children and Adolecents with Cleft Lip and/or Palate. Cleft Palate-Cranio-Facial Journal 28 (4), 347 - 353.

Lidz, T. 1970. The Familiy as the Developmental Setting. In Antohny, E. J. & Koupernik, C. The Child in His Family. The International Yearbook for Child Psychiatry and Allied Disciplines 1. New York: Wiley-Interscience, 19 - 40.

Lilius, P. 1992. Epidemology of Cleft Lip and Palate in Finland 1975 - 1985. The Cleft Center, 1 Department of Surgery, Helsinki University Central Hospital. Helsinki: Yliopistopaino.

Linge, D. E. 1977. Editors Introduction. In Gadamer, H-G. Philosophical Hermeneutics. University of California Press, xi - lvi.

Littlewood, J. 1992. Aspects of Grief: Bereavement in Adult Life. London: Tavistock/Routledge.

Lynch, J. I. (ed.). 1989. Cleft Lip and Cleft Palate. The first four years. Pittsburgh: Cleft Palate Foundation.

Lynch, M. A. 1976. Risk Factors in the Child. A Study of Abused Children and their Siblings. In Martin, H.P. (ed.) The Abused Child: A Multidisciplinary Approach to Developmental Issues and Treatment. Cambridge: Ballinger. Refered to in Parke, R. D. & Lewis, N. G. 1981. The Family in Context: A Multilevel Interactional Analysis of Child Abuse. In Henderson, R. W. (ed.) Parent-Child Interaction. Theory, Research and Prospects. New York: Academic Press, 169 - 206.

Lüscher, K. 1981. Foreword. In Bronfenbrenner, U. 1981. Sosialisaatiotutkimus. (Socialization Research) Transl. by Pirkko Ikonen. Espoo: Weilin+Göös.

Maccoby, E. 1980. Social Development. Psychological Growth and the Parent Child Relationship. New York: Harcourt Brace Jovanovich INC.

Macgregor, F. C.1982. Social and Psychological Studies of Plastic Surgery. Clinics in Plastic Surgery 9 (3). Philadelphia: WB Saunder Company, 285 - 290.

Mahler, M. S., Pine, F. & Bergman, A. 1984. Barnets psykiska födelse. Symbios och individuation. (The Psychological Birth of the Human Infant.) Borås: Natur och Kultur.

Marks, J. 1980. Maternal depression - who is at risk? Health Visitor 53, 7- 9.

May, R. 1986. Den omätbara människan: Om människosynen i existentialistisk psykologi och terapi. (The Discovery of Being, Writings in Existential Psychology) Stockholm: Bonniers

McWilliams, B. J. 1982. Social And Psychological Problems Associated With Cleft Palate. Clinics in Plastic Surgery 9 (3). Philadelphia: WB Saunder Company, 317 - 326.

Mead, G. H. 1972. Mind, Self and Society. Chicago:The University of Chicago Press.

Merleau-Ponty, M. 1962. Phenomenology of Perception. London: Routledge & Kegan Paul.

Middleton, G., Lass, N., Starr, Ph. & Pannbacker, M. 1986. Survey of Public Awareness and Knowledge of Cleft Palate. Cleft Palate Journal 23 (1), 58 - 62

Mishler, E. G. 1986. Research Interviewing. Context and Narrative. Massachusetts: Harward University Press.

Mull D. S. & Mull J. D. 1987. Infanticide Among the Tarahumara of the Mexican Sierra Madre. In Scheper-Hughes N. (ed.) Child Survival. Dordrecht: D. Reidel Publishing Co., 113 - 134.

Määttä, P. 1981. Vammaiset. Suuri vähemmistö. (The Disabled: A Large Minority) Jyväskylä: Gummerus.

Natanson, M. (ed.) 1973. Phenomenology and the Social Sciences. Evanston: Northwestern University Press.

Neisser, U. (ed.) 1993. The Perceived Self. Emory Symposia in Cognition 5. New York: Cambridge University Press.

Niklander, S. 1993. Ensitiedon antajalta vaaditaan tilanneherkkyyttä. (The Giver of Initial Information Must be Sensitive to the Situation) Lapsen Maailma 3, 10 - 12.

Noar, J. H. 1991. Questionnaire Survey of Attitudes and Concerns of Patients with Cleft Lip and Palate and Their Parents. Cleft Palate - Craniofacial Journal 28 (3), 279 - 284.

Nyström, M., Ranta, R. & Kataja, M. 1992. Sizes of Dental Arches and General Body Growth up to 6 years of Age in Children with Isolated Cleft Palate. Scandinavian Journal of Dental Research 100, 1 - 7.

Olim, E. G. 1975. Maternal Language Styles and Cognitive Development. In Rogers, S. (ed.) 1975. Children and Language. Readings in Early Language & Socialization. London: Oxford University Press, 309 - 328.

Oluwasanmni, J. & Adelunkle, O. 1970. Congenital Clefts of the Face in Nigeria. Plastic Reconstruction Surgery 46, 270. Referred to in Strauss, R. P. & Broder, H. 1990. Psychological and Sociocultural Aspects of Cleft Lip and Palate. In Bardach, J. & Morris, H. I. Multidisciplinary Management of Cleft Lip and Palate. Philadelphia: W.B. Saunders Company, 831 - 837.

Ortiz-Monasterio, F. 1975. A Mobile Unit for Reconstruction and Care of Craniofacial Anomalies. Plastic Reconstruction Surgery 1975, 55, 186.

Ostell, A. 1991. Coping, Problem Solving and Stress: A Framework for Intervention Strategies. British Journal of Medical Psychology 64, 11 - 24.

Padwa, B., Evans, C. & Pillemer, F. 1991. Psychosocial Adjustment in Children with Hemifacial Microsomia and Other Craniofacial Deformities. Cleft Palate-Craniofacial Journal 28 (4), 354 - 359.

Parke, R. D. & Lewis, N. G. 1981. The Family in Context: A Multilevel Interactional Analysis of Child Abuse. In Henderson, R. W. (ed.) Parent-Child Interaction. Theory, Research and Prospects. New York: Academic Press, 169 - 206.

Patton, M. Q. 1990. Qualitative Evaluation and Research Methods. Second Edition. Newbury Park: SAGE Publications.

Paynter, E., Edmonson, T. & Jordan, W. 1991. Accuracy of Information Reported by Parents and Children Evaluated by a Cleft Palate Team Cleft Palate-Craniofacial Journal 28 (4), 329 - 337.

Perry, S. E. 1983. Attachment Theory. In Clements, I. & Roberts,F. B. Family Health: A Theoretical Approach to Nursing Care. New York: Wiley & Sons, 110 - 125.

Phillips. A 1991. Winnicott Helsingborg: Wahlström & Widstrand.

Phillips. D C. 1991. Hermeneutics: A Threat to Scientific Social Science? In International Journal of Educational Research 6, 555 - 564.

Piaget, J. & Inhelder, B. 1969. The Psychology of the Child. New York: Basic Book Inc.

Pillemer, F. & Cook, K. 1989. The Psychosocial Adjustment of Pediatric Craniofacial Patients After Surgery. Cleft Palate Journal 26 (3), 201 - 207.

Pillemer, K. & McCartney, K. (eds.) 1991. Parent - Child Relationships Throughout Life. Hillsdale, New Jersey: Lawrence Erlbaum Associates.

Polanyi, M. 1961. Knowing and Being. In Grene, M.(ed.) 1969. Knowing and Being. Essays by Michael Polanyi.Chicago: The University of Chicago Press, 123 - 137.

Polanyi, M. 1962. Tacit knowing: Its Bearing on Some Problems of Philosophy. In Grene, M.(ed.) 1969. Knowing and Being. Essays by Michael Polanyi. Chicago: The University of Chicago Press, 159 - 180.

Polanyi, M. 1964. The Logic of Tacit Inference. In Grene, M.(ed.) 1969. Knowing and Being. Esseys by Michael Polanyi. Chicago. The University of Chicago Press, 138 - 158.

Pojman, L. P. 1978. Kirkegaard's theory of subjectivity and education. In Curtis, B. Mays, W. (ed.) Phenomenology and Education. London: Methuen, 1 - 12.

Rapoport, R., Rapoport, R. N. & Strelitz, Z 1977. Fathers, Mothers and Others. London: Routledge & Kegan Paul.

Repstad, P. 1988. Närhet och distans. Kvalitativa metoder i samhällsvetenskap. (Rapport and Distance. Qualitative methods in Social Sciences) Lund: Studentlitteratur.

Ricoeur, P. 1992. Från text till handling. En antologi om hermeneutik redigerad av Peter Kemp och Bengt Kristensson. (Du texte à l'action. Essais d'herrméneutique, II) Stockholm: Brutus Östlings bokförlag.

Riihinen, O. (ed.) 1992. Sosiaalipolitiikka 2017 Näkökulmia suomalaisen yhteiskunnan kehitykseen ja tulevaisuuteen. (Social Politics 2017: On the Development and Future of the Finnish Society) Juva: WSOY

Rintala, A. 1975. Suomen ensimmäinen huulihalkioleikkaus. (The first Cleft Lip Operation in Finland) Duodecim 91, 1538 - 1545.

Rintala, A. 1976. How a Patient Experienced a Cleft Lip Operation in 1763. Plastic Reconstructive Surgery 57, 158 - 162.

Rintala, A., Ranta, R. Rantala, S -L & Harjula, M. 1986. Halkiclapsi. Helsinki: Yhteistyö Oy.

Ritvanen, A. 1994. Unpublished Report from Finnish Register of Malformations.

Robinson, P. 1987. Perspectives on the Sociology of Education. An Introduction. London: Routledge & Kegan Paul

Rogers, C. 1976. Frihet att lära. (Freedom to Learn) Stockholm: Wahlström & Widstrand.

Rogers, M. T., Barden, R. C. & Kuzai, S. A. 1990. Psychosocial Aspects of Cleft Lip And Palate: The family. In Bardach, J. & Morris, H. I. Multidisciplinary Management of Cleft Lip and Palate. Philadelphia: W.B. Saunders Company, 837 - 839

Rogers, S. (ed.) 1975. Children and Language. Readings in Early Language & Socialization. London: Oxford University Press.

Rosenstein, D. L. & Schulman, J. L. 1990. Family and Social Problems Associated with Cleft Lip and Palate. From: Kernahan, D. A. & Rosenstein, S. W. Cleft Lip and Palate. A System of Management. Baltimore: Williams & Wilkins, 47 - 51.

Rosén-Sandahl, P. 1983. Om barnet inom oss. En introduktion till objektrelationsteori enligt Harry Guntrip. (About the Child within Us. An Introduction to Object-relation Theory, According to Harry Guntrip) Stockholm: Liber Förlag.

Rosenthal, S. B. & Bourgeois, P. L. 1991. Mead and Merleau-Ponty: Toward a Common Vision. New York: State University of New York Press.

Russell, B. 1960. Min filosofiska utveckling. (My Philosophical Development) Stockholm: Natur och Kultur

Russell, B. 1984. The Collected Papers of Bertrand Russel: Theory of Knowledge. The Mc Master University Addition, 7. London: Allen & Unwin.

Räsänen, A. & Väätänen, I. 1986. Kasvun aika: Vammaisen lapsen perheen kriisi. (The Time of Growing: The Crisis of the Family with a Disabled Child) Helsinki: Valtion painatuskeskus.

Salner, M. 1989. Validity in Human Science Research. In Kvale, S. Issues of Validity in Qualitative Research. Lund: Studentlitteratur, 47 - 72.

Schaller, J. 1992. Spädbarnets sociala värld. (The Social World of the Infant) In Hwang, P. (ed.). Barnets tidiga relationer. (Early Relations of the Infant) Borås: Natur och Kultur, 34 - 64.

Scheper-Hughes, N. 1990. Difference and Danger: The Cultural Dynamics of Childhood Stigma, Rejection and Rescue. Cleft Palate Journal 27(3), 301 - 307.

Sartre, J-P. 1977. Being and Nothingness. An Essay on Phenomenological Ontology. London: Methuen & Co.

Seth, A. K. & McWilliams, B. J. 1988. Weight Gain in Children with Cleft Palate From Birth to Two Years. In Cleft Palate Journal 1988 5 (2), 146 - 150.

Siegel, S. 1956. Nonparametric Statistics for the Behavioral Sciences. Tokyo: International Student Edition, McGraw-Hill Kogakusha

Silverman, D. 1989. Six Rules of Qualitative Research. A Post Romantic Argument. Symbolic Interaction 12 (2), 25 - 40.

Singer, E. 1992. Child-care and the Psychology of Development. London: Routledge.

Solnit, A. J. & Stark, M. H. 1961. Mourning and the Birth of a Defective Child. Psychoanalytic Study of the Child , 16, 523 - 537.

Spiegelberg, H. The Phenomenological Movement: A Historical Introduction. (3rev. and enl. ed.) The Hague: Nijhoff.

Spinelli, E. 1989. The interpreted World. An Introduction to Phenomenological Psychology. London: SAGE Publications.

Spitz, R. A. 1965. The First Year of Life. A Psychoanalytic Study of Normal and Deviant Development of Object Relations. New York: International Universities Press INC.

Spitz, R. A. 1975. Hospitalism: In Inquiry into the genesis of Psychiatric Conditions in Early Childhood. In Bronfenbrenner, U. & Mahoney, M. A. (eds.) Influences on Human Development. Second Edition. Hinsdale: The Dryden Press, 168 - 189.

Spriestersbach, D. C. 1973. Psychosocial Aspects of the "Cleft Palate Problem". Iowa City: University Press of Iowa City.

Stark, R. B. 1990. Foreword. In Kernahan, D. A. & Rosenstein, S. W. (eds.) 1990. Cleft Lip and Palate. A System of Management. Baltimore: Williams & Wilkins.

Stern, D. 1982. Ensimmäinen ihmissuhde (The First Relationship) Transl. by Kati Appelqvist. Jyväskylä: Gummerus.

Stern, D. 1994 June. Understanding the Infant through Infant - Mother Interactions. Paper presented at the World Infant Mental Health Congress in Riga, Latvia.

Strauss. A. L. 1988. Qualitative Analysis for Social Scientists. New York: Cambridge University Press.

Strauss, R. P. & Broder, H. 1990. Psychological and Sociocultural Aspects of Cleft Lip and Palate. In Bardach, J. & Morris, H. I Multidisciplinary management of Cleft Lip and Palate. Philadelphia: W.B. Saunders Company, 831 - 837.

Stewart, D & Mickunas, A. 1974. Exploring Phenomenology: A Guide to the Field and Its Literature. Chicago: American Library Association.

Talbot, N. (ed.)1976. Raising Children in Modern America. Boston: Little Brown. Refered to in Rapoport, R., Rapoport, R. N. & Strelitz, Z. 1977. Fathers, Mothers and Others. London: Routledge & Kegan Paul.

Tamminen, T. 1990. Aidin masennus, imetys ja varhainen vuorovaikutus. (Postnatal Depression, Breast-feeding and Mother-Infant Interaction) Series A 304. Academic dissertation. Acta Universitas Tamperensis. English summary.

Taylor, G 1987. Pride, Shame and Guilt Emotions of Self-Assessment. Reprint. Oxford Clarendon Press.

Trevarthen, C. 1993. The Self Born in Intersubjectivity: The Psychology of an Infant Communication. In Neisser, U. (ed.) 1993. The Perceived Self. Emory Symposia in Cognition 5. New York: Cambridge University Press, 121 - 133.

Vandenberg, D. 1974. Phenomenology and Educational Research. In Denton, D. (ed.) Existentialism & Phenomenology in Education. Collected Essays. New York: Teachers College Press, Columbia University, 183 - 220.

Winnicott, D. C. 1983a. Barnet, familjen och omvärlden. (The Child, the Family and the Outside World. Stockholm: Natur och Kultur.

Winnicott, D. C. 1983b. Lek och verklighet. (Play and Reality.) Stockholm: Natur och Kultur.

Yarrow, L. J. & Goodwin, M. S. 1973. The Immediate Impact of Separation. Reaction of Infants to a Change in Mother Figures. In Stone, L. J., Smith H. T. & Murphy, L. B. (eds.) The Competent Infant. New York: Basic Books. Referred to in Maccoby, E. 1980. Social Development. Psychological Growth and the Parent Child Relationship. New York: Harcourt Brace Jovanovich INC.

Yin, R. K. 1984. Case Study Research. Design and Methods. Beverly Hills: SAGE Publications.

Zapf, W. 1993 June. The Effects of Economic Changes on Social Welfare and Health. Paper presented to International Meeting "The effects of Economic Changes on Social Welfare and Health" in Finland in Cooperation with World Health Organisation, Regional Office for Europe, Finland.

Zigler, E. & Hall, N. W. 1990. Child Abuse in America. In Cicchetti, D. & Carlsson, V. (eds.). Child Maltreatment. Theory and Research on the Causes and Consequenses of Child Abuse and Neglect. New York: Cambridge University Press.

Åkerberg, H. 1986. Hermeneutik och pedagogisk psykologi. Premisser för tolkning och förståelse inom beteendevetenskap. (Hermeneutics and Educational Psychology. Premises for Interpretation and Understanding in Behavioral Sciences) Stockholm: Norstedts.

Öfverlund, J. 1993. Vauvan kommunikaatiotaitojen kehitys - puheen oppimisen perusta. (The Development of the Infant's Communication Abilities - the Basis of Learning to Talk) In Iivonen, A. & Lieko, A. & Korpilahti, P. (eds.) Lapsen normaali ja poikkeava kielen kehitys. (Normal and Deviant Development of Language) Helsinki: Suomalaisen kirjallisuuden seura.

Appendix

Mothers are sorted horizontally and topics vertically. Table numbers are same as in Chapters 4 and 5. Non-numbered topics are not tabled.

Table	Mothers	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
	Topics and Shortened answers															
6	***Feelings at the Cild's Birth***	*2*	*4*	*1*	*1*	*2*	*2*	*2*	*3*	*3*	*2*	*2*	*2*	*2*	*2*	*2*
	It can't be true, I will soon wake up							x								
	I cried		x							x						
	I did not feel anything															
	I do not remember what I felt								x							
	Felt sorry for the child		x							x						
	I said that I didn't want this child															
	What else will it have														x	
	Is it my fault?															
	I was not a shocked, I knew that it could be fixed															
	It does not matter															
	It frightened me	x					x				x					
	It was a shock							x					x		x	
	I was afraid that the child would die															
	Pleased with baby's gender															x
	I was pleased at that moment					x										
	Disappointed with baby's gender															
	It confirmed my suspicions/something was wrong	x	x			x	x		x	x						
	I did not understand		x						x		x	x				x
	It was a disappointment			x												
	I have failed											x				
	Felt relieved that it was not anything worse												x	x		
	I was in a big happy cloud with a small black spot													x		
	I thought about what other people would think				x											
	We have got a baby, how wonderful it is															
	Description of Infant as a Person	*0*	*1*	*1*	*0*	*1*	*1*	*1*	*1*	*0*	*1*	*0*	*0*	*0*	*0*	*1*
	Stamina					x										
	Easy, kind		x	x			x	x								
	Charming person, fantastic child															x
	Full of vitality										x					
	Difficult								x							
	Smarter than other kids															
	Description of Infant's Appearance	*0*	*0*	*0*	*0*	*0*	*0*	*0*	*0*	*2*	*2*	*1*	*0*	*0*	*0*	*0*
	I didn't like his small chin															
	An ugly little monkey															
	Looked terrible									x						
	A terrible monster (as a joke)															
	No beauty, with such lips															
	Worse through a mirror									x	x					
	Photographs remind you															
	Quite OK															
	To me a beautiful child															
	Healthy and beautiful															
	The face looked like a barrel											x				
	Beautiful despite of the cleft										x					
	Not bad looking															
	Looked as if he smiled all the time															
	Sweet															
	I did not see the cleft															
	Has to be considered sweet															
11.1	***Mothers' feelings About Surgery***	*1*	*1*	*2*	*1*	*3*	*2*	*1*	*2*	*2*	*1*	*1*	*1*	*1*	*1*	*1*
	Worse than when the baby born															
	I was impatient	x	x	x		x	x		x				x		x	
	Afraid because of the risks (that baby will die)						x									
	A shock when I saw the baby after surgery										x					
	I did not recognize the baby after surgery					x		x		x						
	I was nervous								x	x						x
	I was not nervous				x											
	I had a breathing spell					x										
	Surgery did not change its appearance											x				
	It was difficult to leave the baby at the hospital			x										x		

16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	Total
2	3	1	2	2	2	3	1	3	1	2	2	3	3	2	2	2	2	2	1	2	1	2	1	1	80
								x				x													3
				x		x						x					x								6
										x				x					x						3
					x																				2
									x														x		4
							x																		1
															x					x					3
								x																	1
											x														1
											x			x								x			3
	x	x													x					x	x			x	9
				x	x			x				x	x			x		x							10
			x															x							2
													x												2
																									1
										x															1
																x	x								8
			x			x							x												8
x	x																								3
x																									2
	x																					x			4
																									1
																									1
						x																			1
0	0	0	1	1	1	2	1	1	0	0	1	1	1	0	2	0	0	2	1	0	1	0	1	0	25
				x		x	x					x						x			x		x		8
					x			x			x		x												8
																		x	x						3
															x										2
						x									x										3
			x																						1
1	1	0	0	1	1	2	1	1	1	1	2	2	1	2	1	1	2	0	0	1	1	3	2	2	35
	x																								1
												x													1
x							x	x	x			x													6
																				x		x			2
																x									1
						x					x		x	x								x	x		8
														x			x					x	x	x	5
															x										1
						x																			1
				x																					1
																									1
																									1
											x													x	2
																					x				1
					x																				1
										x															1
																	x								1
2	1	1	1	1	3	2	1	1	1	1	1	2	1	1	1	2	3	2	2	1	3	2	3	3	63
									x					x							x	x		x	5
	x		x	x	x		x	x				x				x	x				x			x	19
		x																x	x	x			x		6
					x						x						x				x	x			6
x						x				x		x	x			x	x						x		11
x					x													x	x				x	x	9
																									1
						x									x										3
																									1
																									2

Table	Mothers	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
	Topics and Shortened answers															
11.2	***Staying with the Child at the Hospital***	*1*	*1*	*1*	*1*	*1*	*1*	*1*	*1*	*1*	*1*	*1*	*1*	*1*	*1*	*1*
	Stayed/wanted to stay day and night with the child		x									x				
	Stayed the whole day with the child	x				x	x		x	x	x		x	x	x	x
	Stayed with the child part of the time			x												
	Visited the child every day, but did not stay all day				x			x								
	Left the child at the hospital															
11.3	***Other Experiences of Separation***	*1*	*1*	*1*	*1*	*1*	*1*	*1*	*1*	*1*	*1*	*1*	*1*	*1*	*1*	*1*
	No other experiences	x				x	x		x	x	x	x	x	x	x	x
	Separation after birth		x	x				x								
	I have been on a trip															
	No descreption				x											
7	***Mothers' Descriptions of Early Bonding***	*2*	*1*	*1*	*1*	*1*	*1*	*2*	*1*	*1*	*2*	*2*	*1*	*1*	*1*	*1*
	I would not have changed the baby									x						
	When I took her in my arms, I forgot everything															
	I am more care-giving, that's the way it should be															
	I love the baby		x								x	x				
	I hesitated to take care of the child at the beginning															
	I hated her in the beginning															
	Husband was closer															
	It took a long time before I could attach to the child															
	I love this child more than it's sibling(s)													x	x	
	I love this child more because of the cleft	x														
	I love all my children equally			x												
	The baby was wonderful despite the cleft															
	I am proud of my child								x							
	I have been thinking about my child as a healthy one															x
	Mother does not talk about bonding issues				x											
	We had planned for this child, no problems												x			
	The child was not planned for/difficult beginnig							x								
	I did not take enough notice of the baby															
	I thought I'm going to kill this baby										x					
	The child is clinging, which I think is heavy					x										
	It's very difficult for me to leave the child						x					x				
	I don't have time/energy to carry the child all the time															
	I got used to it very soon after the birth															
	The child is so sweet/immediately in my arms if crying															
	I had difficulties to understand the child	x						x								
12	***Expressions of Emotions During First Year***	*3*	*2*	*0*	*0*	*1*	*1*	*0*	*0*	*0*	*1*	*2*	*0*	*0*	*2*	*2*
	After half year strong negative feelings arose	x													x	x
	I was afraid of additional problems	x	x								x				x	
	I have been bitter															
	I have been very depressed															
	I never became a woman											x				
	I was over-energetic and strong in beginning	x					x									x
	Why did it happen to me?		x			x										
	No use ask "why me?"															
	I prepared myself to have to give the baby away															
	I built myself a prison and punished myself											x				
8a	***Descriptions of Feeding Situation, Liquid***	*3*	*4*	*3*	*3*	*4*	*5*	*2*	*3*	*2*	*2*	*3*	*4*	*1*	*4*	*4*
	Breast-feeding													x		
	Extracting breast-milk with a pump for some time	x	x	x		x	x		x		x	x	x		x	x
	Giving milk mixture from the beginning				x			x		x						
	Tube-feeding in the beginning		x													
	The feeding succeeded well with a nipple/big hole				x	x	x		x						x	x
	Difficult at the beginning	x		x		x		x	x	x		x	x			x
	A lot of difficulties		x								x					
	Disappointment that I could not breast-feed the baby			x	x	x	x					x	x		x	
	I was proud of giving breast-milk	x	x				x						x			x
	No particular problems						x								x	

16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	Total
1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	40
																						x			3
x	x	x	x	x	x	x		x	x	x	x	x	x	x		x	x	x	x		x		x	x	31
																									1
							x																		3
															x					x					2
1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	40
x		x	x	x	x	x	x	x	x		x	x		x					x	x	x	x		x	28
	x									x					x	x	x	x					x		10
													x												1
																									1
4	2	2	1	0	1	1	2	2	1	1	1	0	1	1	1	1	4	1	1	2	2	0	1	1	53
																									1
								x																	1
																	x								1
														x			x			x			x		7
x															x		x								3
x																	x								2
x							x													x					3
x							x									x									3
					x								x					x							5
			x						x		x														4
																									1
								x																	1
						x															x				3
		x																	x		x				4
																									1
																									1
																									1
		x																							1
																									1
																									1
																									2
	x																								1
										x															1
																								x	1
	x																								3
2	1	0	1	1	1	2	2	3	2	3	3	2	1	0	4	2	1	4	1	1	1	2	1	1	56
						x			x	x	x	x						x	x					x	11
x	x		x	x			x	x	x	x	x	x			x		x	x		x	x	x			20
															x	x									2
					x										x										2
																									1
						x		x		x	x							x							8
							x	x					x		x	x		x				x			9
																							x		1
x																									1
																									1
2	4	2	2	4	1	2	3	2	3	2	3	2	4	1	4	3	3	3	1	3	1	1	1	1	105
					x									x					x		x	x	x	x	8
x	x		x	x		x		x	x		x	x	x		x		x	x							24
		x					x			x						x				x					8
	x														x			x							4
				x			x				x		x			x	x			x					13
	x	x	x	x		x	x	x	x		x				x	x		x							21
x										x		x													5
	x			x									x		x										11
									x																6
													x				x			x					5

BEST COPY AVAILABLE

Table	Mothers	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
	Topics and Shortened answers															
6b	***Descriptions of Feeding Situation, Solid***	*1*	*1*	*1*	*2*	*1*	*1*	*1*	*1*	*1*	*1*	*1*	*1*	*1*	*1*	*1*
	No particular problems				x											x
	Not very much trouble							x	x	x	x					
	No description				x							x			x	
	Difficulties at the beginning	x		x		x	x							x		
	A lot of difficulties		x										x			
10	***Descriptions of the Weight-Gain of Child***	*1*	*1*	*1*	*1*	*1*	*1*	*1*	*1*	*1*	*1*	*1*	*1*	*1*	*1*	*1*
	Very good	x				x										
	Good			x						x				x	x	x
	Problems at the beginning, then normal							x	x				x			
	Somewhat slow															
	Not good		x		x						x	x				
	No description						x									
•	***Talking about Baby's Cleft/Friends, Relatives***	*1*	*2*	*1*	*1*	*2*	*2*	*1*	*1*	*1*	*2*	*1*	*1*	*2*	*2*	*1*
	Matter-of- fact manner					x	x		x	x						
	Both told										x					
	Husband told															
	Not difficult to talk											x			x	
	Difficult to talk		y								x					
	Disappointed at some relatives/friends			x				x					x	x		
	I had to give therapy to my relatives															
	Only one in same situation understood															
	Discussed telling/not telling															
	Only told few very close relatives/friends															
	Relations to own relatives broken				x											
	They did not understand	x														x
	I told it to 3 people, but not to my sister															
	I hid information from my own family														x	
	Some relatives asked not to tell enyone		x			x	x							x		
•	***Talking about Baby's Cleft/Strangers***	*2*	*1*	*1*	*0*	*1*	*1*	*0*	*1*	*1*	*0*	*0*	*1*	*0*	*0*	*0*
	Not difficult	x					x			x						
	Felt tired of explaining															
	A tape started															
	Difficult		x			x										
	Got hurt, as othars saw her odd															
	I told everybody	x							x							
	I did not tell to anybody			x									x			
•	***Showing the Child to Friends/Relatives***	*0*	*0*	*0*	*0*	*1*	*0*	*2*	*1*	*1*	*1*	*0*	*0*	*0*	*0*	*0*
	Not difficult															
	Matter-of-fact manner					x			x	x						
	Some were encouraging															
	Difficulties with some relatives							x			x					
	Difficulties with some friends							x								
	Playing roles															
16	***Showing the child to strangers***	*0*	*1*	*0*	*0*	*2*	*0*	*2*	*1*	*1*	*2*	*0*	*0*	*0*	*0*	*0*
	I felt ashamed, did not want to show															
	It was difficult, but did not want to hide child					x			x		x					
	People felt pity for the child															
	People are stareing at the child					x					x					
	I did not feel ashamed															
	Did not take the child anywhere at the beginning							x								
	I wish it would not be visible															
	I turned his head/tho clefted side not would be visible															
	I was afraid that people would notice the cleft															
	People are curious		x					x		x						
	No problems															
	I told the neigbors kids that he had an accident															

16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	Total
1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	0	1	1	1	1	1	1	1	40
	x				x									x						x		x	x	x	9
						x																			5
x							x		x									x	x		x				9
		x		x				x			x		x		x	x									12
			x							x		x													5
1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	40
								x												x					4
					x		x		x		x		x	x	x	x					x		x	x	16
			x			x												x							6
				x						x															2
x	x	x										x					x								9
																			x			x			3
1	2	1	1	2	1	2	1	1	1	2	1	0	2	2	1	1	2	4	1	0	2	2	2	3	59
				x	x					x				x					x			x	x	x	12
													x				x	x							4
							x			x														x	3
	x							x	x					x	x						x				8
																x	x								4
	x					x					x							x			x	x	x	x	12
						x												x							2
																		x							1
													x												1
				x																					1
			x																						2
																									2
x																									1
																									1
		x																							5
1	2	0	0	0	1	1	1	1	0	0	1	1	1	2	1	1	0	1	0	1	1	1	0	1	28
	x				x																x	x		x	8
						x		x			x	x		x											5
													x	x						x					3
							x								x	x									5
																		x							1
	x																								3
x																									3
0	0	0	0	0	1	1	1	1	1	0	1	1	1	0	1	1	1	1	0	0	2	1	0	1	22
					x				x																2
							x	x							x		x				x	x		x	10
																x									1
						x					x		x								x				6
												x													2
																		x							1
1	0	0	0	0	1	2	1	2	1	0	1	1	1	0	1	1	1	1	0	1	1	1	2	1	30
							x																		1
						x			x		x												x		7
																				x					1
						x							x									x	x		6
								x																	1
												x			x		x	x							5
								x																	1
																x									1
x																									1
					x																				4
																								x	1
																					x				1

Table	**Mothers**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**	**15**
	Topics and Shortened answers															
13	***The Information the Mother Got at Hospital***	*2*	*2*	*2*	*2*	*3*	*2*	*1*	*3*	*2*	*2*	*4*	*2*	*2*	*2*	*2*
	No or practically no oral information			x								x			x	
	Got yellow booklet					x			x	x	x	x	x	x		
	Got old booklet											x				
	Wrong information about time/place of the surgery													x		
	No information about feeding the baby			x						x						
	Got information about feeding the baby		x		x				x						x	x
	Got information about time/place of the surgery		x		x		x		x				x			x
	Wrong information about feeding the baby	x										x				
	Got information from contact-person	x				x					x					
	Satisfied with information					x		x								
	Other wrong information															
	Knew about cleft						x									
	Explanation of What Caused the Cleft	*1*	*1*	*1*	*0*	*2*	*3*	*1*	*1*	*1*	*1*	*1*	*1*	*1*	*3*	*1*
	Air trip, security arrangements					x										
	Clomifen-pregnancy											x				
	Epileptic medicine															
	Coincidence														x	
	Contraction medicine															
	Yeast medicine															
	A flu			x						x						x
	Pollution						x									
	In the family	x	x													
	Anesthetic gas															
	Cigarette smoking							x								
	Anorexia															
	Too much alcohol at a party														x	
	Repair and painting job															
	Work with patients/strong chemicals						x									
	A chemical															
	Workstation radiation					x										
	Age														x	
	Haven't found any reason								x				x			
	A-vitamin (Retinol)						x									
	Did not discuss													x		
	Workplace was pesticided															
	Heavy work															
	I was frightened										x					
	Bleeding															
	Having More Children	*0*	*1*	*1*	*0*	*1*	*0*	*0*	*0*	*1*	*1*	*0*	*2*	*1*	*1*	*1*
	No and cleft is the reason												x			
	No, but cleft is not the reason			x									x		x	
	No, afraid to get child with handicap		x													
	The cleft is the reason for hesitating										x			x		
	Maybe ?															
	Yes, but not now					x				x						
	Yes, hopefully no cleft															
	Yes, I am pregnant															x
	Presentiments	*1*	*1*	*0*	*0*	*1*	*1*	*0*	*1*	*1*	*0*	*0*	*0*	*0*	*0*	*0*
	No surprise	x	x			x	x		x	x						
9	***Mothers' Explanations** of **Their Acceptance***	*1*	*1*	*1*	*0*	*0*	*2*	*0*	*1*	*1*	*0*	*0*	*1*	*1*	*1*	*1*
	Not first child						x									
	Not visible	x		x												
	A boy															
	not a big problem, it can be fixed		x				x		x	x			x	x		
	I decided that child is healthy														x	x
	I decided that the child is smarter than other children															
	No problem, since I could breast-feed the baby															
17	***The Meaning of the Occurrence***	*1*	*2*	*0*	*0*	*2*	*0*	*1*	*1*	*1*	*2*	*0*	*0*	*1*	*0*	*0*
	To come closer to God		x													
	Improvement of my own personality	x	x			x		x	x		x					
	I did not need this to develop										x					
	Better that this child was born to us															
	I would like to help other people in the same situation					x				x				x		
	Total	*24*	*29*	*19*	*14*	*31*	*27*	*20*	*25*	*25*	*26*	*21*	*20*	*17*	*23*	*21*

16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	Total
3	2	2	3	1	1	3	2	1	2	1	2	3	3	1	1	2	1	3	1	2	3	1	2	2	81
			x				x		x			x			x				x						9
x	x	x				x		x				x	x			x	x			x	x	x	x	x	21
											x							x							3
			x										x							x	x				5
x			x				x		x		x										x				8
	x	x				x																			8
														x										x	8
				x														x							4
					x							x	x			x		x							8
										x													x		4
x						x																			2
																									1
1	2	0	2	0	1	1	2	2	1	1	2	1	2	1	2	1	2	1	2	2	1	1	2	1	53
																									1
																									1
x																									1
			x																						2
			x																						1
									x																1
	x					x	x				x				x						x			x	10
	x				x		x																		4
								x			x						x			x		x	x		8
																				x					1
								x											x						3
												x													1
																		x	x						3
													x												1
																	x								2
																x									1
															x										2
																									1
														x											3
																									1
																									1
																							x		1
										x															1
																									1
													x												1
1	1	0	1	1	1	1	1	1	1	0	1	1	1	1	1	1	1	1	0	0	0	1	1	1	30
					x																				2
				x			x		x		x			x	x								x		10
												x				x									3
x						x							x												5
																	x	x				x			3
																								x	3
	x		x					x																	3
																									1
0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	1	0	0	0	0	0	0	0	8
																x	x								8
1	1	1	2	1	0	0	1	0	1	0	0	2	1	1	0	1	2	0	1	1	2	1	0	1	32
				x								x					x								4
	x																								3
							x										x				x				3
		x	x						x			x	x			x				x		x		x	15
																			x		x				4
x			x																						2
														x											1
0	1	0	0	0	0	0	0	0	1	0	0	1	1	0	1	0	1	0	0	0	0	1	0	0	18
												x													2
									x								x								8
																						x			2
	x														x										2
													x												4
28	27	14	21	19	21	29	25	26	22	18	26	27	29	19	28	25	30	30	16	21	26	24	23	24	938

HELSINGIN YLIOPISTON
OPETTAJANKOULUTUSLAITOS

ISBN 951-45-6924-5
ISSN 0359-4203

Yliopistopaino
1995