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Study of information shared between children with cleft lip and/or palate and their care-givers with regard to the cleft condition and its treatment

Jodie L. Egosque

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A STUDY OF INFORMATION SHARED BETWEEN CHILDREN
WITH CLEFT LIP AND/OR PALATE AND THEIR
CARE-GIVERS WITH REGARD TO THE CLEFT CONDITION
AND ITS TREATMENT

By
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B.A., University of Montana, 1988

Presented in partial fulfillment of the requirements
for the degree of
Master of Arts
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1990

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Chairperson/Board of Directors

Dean/Graduate School

August 2, 1990
A Study of Information Shared between Children with Cleft Lip and/or Palate and their Care-givers with Regard to the Cleft Condition and Its Treatment (90 pages)

Director: Alice E. Smith, M.A.

This study addressed information shared between children with cleft lip and/or palate and their care-givers regarding the cleft condition and its treatment. The purpose of the study was to determine if children with cleft lip and/or palate and their care-givers who receive services in a non-hospital setting in Montana share the same information regarding cleft lip and/or palate and its treatment.

Participants for this study were contacted through the Comprehensive Development Center in Missoula, Montana. All participants had participated in the Comprehensive Development Center's Cleft Palate Clinic. Ten children with cleft lip and/or palate ranging in age from six years to 19 years and their primary care-giver served as subjects as did four professionals (a surgeon, an orthodontist, a speech therapist, and a social worker). Interviews were conducted using a questionnaire made up of close-ended and open-ended questions.

A descriptive analysis indicated that children and parents share approximately 50% of the information requested in this study. The unshared areas of information included the reasons for attending the cleft palate clinic and which professionals were seen, the number of operations the child had had, the reasons for inserting PE tubes, who was providing information, and social effects of having a cleft lip and/or palate.
ACKNOWLEDGEMENTS

This author would like to thank her thesis committee, Ms. Alice Smith, Dr. Jesse Kennedy, Dr. Charles Horesji, and Dr. Mike Jakupcak for their efforts in completing this study. Special thanks to Ms. Alice Smith for her time and patience during this process.

Thanks are also extended to Ms. Kari Altenhofen and the secretaries at the Comprehensive Development Center in Missoula, Montana for their help with the data collection portion of this study.

Special thanks are extended to the family who participated in this study just days after they lost their home in a fire.

Finally, thanks are extended to my own family, without whose support and understanding, this project would not have been completed. This paper is dedicated to my husband, Brian, my children, Susan and Tyler, and my father and mother, Orville and Carole Isakson.
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Chapter I

INTRODUCTION

The term counseling can have many definitions. Leuterman (1984) has pointed out counseling means different things to different people. Professional approaches involve a wide range of counseling behaviors including direct environmental manipulation, advice-giving, persuasion, confrontation, and providing an accepting relationship with the client.

Not only can the definition vary, the primary purpose of counseling changes from one professional to the next. Webster (1977) indicated that the primary purpose of counseling is to provide an accepting environment for family members to express their thoughts and feelings and, secondarily, to receive information about the disorder affecting the individual or family member.

Bricklin (1970), however, when writing about counseling parents of children with disabilities indicated that the primary goal of counseling is to provide information about the disorder, the etiology, if known, and the prognosis. A secondary goal is to help parents recognize their reactions and cope with their feelings, enabling them to focus their energies on helping the child.
McFarlane, Fujiki, and Brinton (1984) indicated that not only do parents have to deal with their child's disability and make plans for them, but they also have to live with the results of those plans long after professionals involved with the child are gone. Therefore, accurate information about diagnostic results, clinical impressions, and remediation plans is vital.

Buscaglia (1975) suggested anecdotally that information is the vital ingredient in counseling and agrees with McFarlane et al. (1984), that the terminology used in informative counseling may make a difference for the parents and child between confusion and understanding of the problem. Using direct, easily understood language is essential for effective communication during counseling. In addition to appropriate terminology, openness regarding the problem is necessary to avoid inappropriate anxieties and fears about the problem (Buscaglia, 1975). Debuskey (1970) stated anecdotally that most young patients respond more favorably to treatment and adjust better to their illness if they understand the nature of the problem and the necessity of treatment. Gold, Bales, Lyles, and Drezner (1989) studied 38 chronically ill subjects enrolled in a program that included intensive education about their illness, physical therapy education, nutritional counseling, and medical evaluation and treatment. These researchers
concluded that the subjects enrolled in the program
demonstrated improved future outlook, mention of depression
decreased, knowledge of the illness increased, and there
were meaningful changes in the subjects' understanding of
treatment and management of their illness.

Many children born with a cleft lip and/or palate are
seen by a team of professionals (surgeon, orthodontist,
speech pathologist, etc.) in a cleft palate clinic. The
settings of these cleft palate clinics appear to vary. A
cleft palate clinic may be associated with a hospital, as is
evidenced by studies of children receiving services in this
setting. Some cleft palate clinics may be associated with
non-hospital agencies. Regardless of the setting, children
with cleft lip and/or palate receiving services in a cleft
palate clinic are evaluated by a team of professionals who
recommend a course of treatment. Every aspect of the cleft
lip and/or palate is assessed separately and as a whole for
each child. Morris, Jakobi, and Harrington (1978) indicated
that, in addition to evaluation and treatment
recommendations, each professional on the team is
responsible for counseling the parent. Walesky-Rainbow and
Morris (1978) assessed the informative counseling procedures
used and the knowledge base of children with cleft lip
and/or palate receiving services in a hospital based cleft
palate clinic. However, to date no studies have looked at
the knowledge base of parents and children receiving services in a non-hospital cleft palate clinic.

The present study is concerned with the type and extent of counseling information received by children with cleft lip and/or palate and their parents. The following sections of this chapter will discuss children with cleft lip and/or palate, their parents, the types of information both receive about the nature and treatment of the cleft, roles of cleft palate team professionals, and various aspects of counseling involved in these cases. The chapter concludes with a statement of the problem.

Children

Children diagnosed with cleft lip and/or palate must undergo what most would agree are negative experiences (Debuskey, 1970; Lipkin and Cohen, 1973). These experiences might include surgery, hospitalization, and changes in parent-child relationships brought on by treatment of the problem. As mentioned earlier, Debuskey (1970) indicated that most young patients respond more favorably to treatment and adjust better if they have an understanding of the problem and the need for treatment.

Spriestersbach (1973) investigated the nature of the information-giving process used with children with clefts. His primary investigative tool was a pre-coded case history. He interviewed 175 children with cleft lip and/or palate
concerning aspects of their treatment, amount of counseling they received, and the effectiveness of that counseling. While most of these children reacted positively to their programs of treatment, Spriestersbach (1973) found that 38% stated that no one had explained the nature of past surgery, nor the reasons for it, and half of the children indicated that they wished they knew more about future treatment.

Walesky-Rainbow and Morris (1978) studied 32 children with cleft lip and/or palate and their parents to assess the type and extent of knowledge each possessed about the problem. Their conclusions indicated that as a child matures, so does his/her need for information, and at some time counseling should be directed to the child rather than just to the parent to avoid the misunderstanding that may come from not knowing about past procedures and what the future holds. The investigators also found that professionals were inconsistent with regard to the type and extent of information they thought should be provided for the child. Walesky-Rainbow and Morris (1978) found that children demonstrated a limited knowledge base concerning cleft lip and/or palate and its treatment.

No studies were identified which investigated the knowledge base of children with cleft lip and/or palate who received services at a non-hospital cleft palate clinic. Previous studies have used subjects who received services at
cleft palate clinics in hospital settings. Studies have indicated that children who have clefts of the lip and/or palate tend to adjust and accept the condition better if they possess more information about the condition itself, treatment, and possible end results. Therefore, a need exists to identify the knowledge base of children in a non-hospital setting to determine if differences exist between the non-hospital and the hospital setting. The next section will discuss the counseling needs of parents of children with cleft lip and/or palate.

Parents

Parents with a child with cleft lip and/or palate may face special problems directly related to the disability. While investigating the knowledge base of parents with children with cleft lip and/or palate, Tretsven (1965), Crocker and Crocker (1970), and Van Demark and Van Demark (1970) found some parents possessed inadequate knowledge about cleft lip and/or palate. McDonald (1979) studied the needs of parents of children with cleft lip and/or palate and reported that parents look to the professionals for information, reassurance, and appropriate treatment for their children. McDonald also pointed out that without honest information parents tend to arrive at the wrong conclusions about the problem and treatment leading to anxiety and fear for both the parents and the child.
Walesky-Rainbow and Morris (1978) indicated that misunderstanding and misinformation during the time of critical decision making and acceptance of the cleft condition can be devastating in that parents may carry these impressions with them for a long time. Misunderstandings and misinformation potentially leads to anxiety for the parents and their child. Walesky-Rainbow and Morris (1978) suggested that professionals tend to encourage parents to provide information regarding the cleft condition to their child. They indicated the need for this information even though the study demonstrated that professionals do not think parents can provide accurate and sufficient information. It was demonstrated that the mothers had appropriate knowledge and the children did not, especially with regard to what a cleft is, the etiology of the condition, aspects of future surgery, and the relationship between a cleft and the production of speech. This study indicated that mothers were poor predictors of their child's responses, which may imply that their effectiveness as information-givers is limited or that there is ineffective communication.

The literature reviewed focusing on the extent of information the parents receive in a hospital setting concerning the cleft condition and its treatment indicates that the knowledge base is inadequate. No studies have been
identified that looked at the information parents receive in a non-hospital cleft clinic. It is possible that the type and extent of information received varies between a hospital and non-hospital setting. Therefore, a need exists to determine the type and extent of knowledge the parent of a child with a cleft of the lip and/or palate receives in a non-hospital cleft palate clinic to determine if a difference exists in the type and extent of information provided in each setting. The next section will discuss the professionals involved with children with cleft lip and/or palates.

Professionals

When a child is diagnosed as having a cleft lip and/or palate, he/she and the family may become involved with various professionals, numerous treatment plans, and a long-term commitment in each area. The professionals usually work as a team, but each has a specific goal or task in mind. The role of the attending physician might not include being on the team, but he/she is responsible for insuring immediate survival and adequate feeding, diagnosis of associated defects, and referring the family to a treatment team for treatment planning. This physician usually begins counseling the parents about the cleft and general management (Morris et al., 1978). According to Morris et al. (1978) the cleft palate team may consist of
representatives from surgery, dentistry, speech pathology, pediatrics, otolaryngology, social service, psychology, nursing, audiology, genetics, and radiology. The general objectives of the medical members of the team are to provide total health care and to participate in counseling about the defect and general management aspects. The team dentists provide total dental care in cooperation with the family dentist and participate in counseling about the defect and general management. Speech and hearing representatives provide services for communication disorders in cooperation with local clinicians and participate in counseling about the defect and management. Psychosocial members provide services for intellectual, personality, and social disorders and participate in counseling. The present study will focus on the surgeons, orthodontists, speech pathologists, and social workers as they are the professionals associated with the Walesky-Rainbow and Morris (1978) study.

Morris et al., (1978) indicated that the professionals working with the child are responsible for counseling the parents. However, no mention was made in the literature about who is responsible for informing the child. Walesky-Rainbow and Morris (1978) indicated that parents may not be effective information-givers. At the same time, Buscaglia (1975) and McFarlane et al., (1984) indicated that information about the cleft and treatment is vital and
necessary to avoid anxiety and fear about the problem. Walesky-Rainbow and Morris (1978) addressed what professionals thought children and parents should know about the cleft condition and treatment and indicated that the more information given to parents and children the more capable they are of understanding and dealing with the potential problems they face with regard to long term care of the cleft condition. All studies reviewed investigated the type and extent of information professionals provide parents and children receiving services in hospital cleft palate clinics. No studies were identified which explored the type and extent of information professionals in non-hospital cleft palate clinics provide children with cleft lip and/or palate and their parents. It is important to determine if differences exist between the hospital and non-hospital settings and what these differences may be. Determining these differences may lead to better services which may, in turn, lead to better understanding of and adjustment to cleft lip and/or palate and its treatment.

Statement of Problem

The literature reviewed indicates a need for information regarding cleft lip and/or palate and its treatment by children with the cleft and their parents. Studies based in hospital cleft palate clinics suggest that information regarding the cleft condition and its treatment
provided to children with clefts or their parents may be inadequate according to what researchers suggest parents and children need to know. Spriestersbach (1973) and Walesky-Rainbow and Morris (1978) indicated that the more information regarding the cleft condition and its treatment that is available to parents of children with a cleft condition and to children with the cleft condition the more capable they are of dealing with potential problems that may arise concerning the condition. However, these studies go further to indicate that children do not possess accurate and adequate information regarding their cleft condition and treatment. These studies were based in hospital cleft palate clinics. No studies were identified which looked at the type and amount of information provided children with cleft lip and/or palate and their parents in a non-hospital setting. Therefore, the possibility of differences between the hospital and non-hospital setting has not been explored. Thus, a need exists to explore the type and extent of information concerning the cleft condition and its treatment provided to children with cleft lip and/or palate and their parents within a non-hospital setting to determine if differences exist, what these differences may be, and the implications the differences may have on improving services and future research.
Purpose of the Present Study

The purpose of the present study is to test the following hypothesis:

Children with cleft lip and/or palate and their caregivers who receive services in a non-hospital cleft palate clinic setting in Montana do not share the same body of knowledge regarding cleft lip and/or palate and its treatment.
Chapter II
METHODS

Subjects

Ten children with cleft lip and/or palate ranging in age from 6 years to 19 years and their primary care-giver served as subjects. Subjects resided in Montana and took part in the Comprehensive Development Center's Cleft Palate Clinic in Missoula and Kalispell. All subjects were contacted through the Comprehensive Development Center in Missoula, Montana. Approximately 60 letters were mailed out explaining the study and requesting participation (Appendix A). Each family which volunteered was contacted by the investigator and an appointment was arranged at the family's convenience for the interview.

All children met the following criteria:

1. Normal limits of intellectual functioning were determined by appropriate grade placement within one year.

2. Each child was in some phase of a cleft palate treatment program, either surgical, dental or speech therapy.

3. The child was not currently receiving professional help for behavioral problems as per parent report.

4. Other major disabilities had not been diagnosed.

5. The child had received most of his/her primary
care and recommendations from the Comprehensive Development Center's cleft palate team of professionals.

All primary care-givers met the following criteria to be included in this study:

1. The care-giver had not received any formal training in cleft lip and/or palate.

2. The care-giver was not a surgeon, orthodontist, social worker, speech pathologist, and did not belong to any other profession that routinely provides care for cleft lip and/or palate.

3. The care-giver did not have a cleft condition.

4. The care-giver had received most of his/her information and recommendations concerning the child's cleft lip and/or palate from the Comprehensive Development Center's cleft palate team of professionals.

All professionals were volunteers (Appendix A). The professionals involved in this study were members of the Comprehensive Development Center's cleft palate clinic with the exception of the social worker. Each professional was contacted by the investigator and an appointment was arranged at each professional's convenience for an interview.
Materials

Three questionnaires were used in this study. (Appendix B).

1. Form A was administered to the children. It consisted of 81 questions in four basic areas:
   a) The first 17 questions were designed to elicit general knowledge about the child's cleft condition and treatment. These questions were designed in a "Yes, No, I don't know" format.
   b) The next 43 questions were designed to elicit information about the surgical, dental, speech, and social aspects of the child's cleft condition and treatment, as well as sources of the information given to the child and level of understanding of the information. These questions were designed in a "Yes, No, I don't know" format.
   c) The next 15 questions were designed in an open-ended manner to allow the child to answer the previous questions in his/her own words. These probe questions were asked in the hopes of eliciting further information about the cleft condition and its treatment.
   d) The final six questions were designed to describe aspects of the information giving process provided
by the care-giver concerning the child's cleft condition and its treatment.

2. Form B consisted of 81 questions. This questionnaire was administered to the care-giver and consisted of questions in the four previously mentioned areas.

3. Form C was used to interview four of the professionals who worked with children with clefts at the cleft palate clinic. The majority of these questions were designed to elicit information the professionals routinely provided children with cleft lip and/or palate and the primary care-giver. Each professional was then asked more specific questions regarding information related to their particular field of expertise.

The Interviews

Setting. Data collection involving the child and care-giver took place in a room at the University of Montana Speech, Hearing, and Language Clinic, equipped with a table and chairs, or, if the subjects were not living in the Missoula area, by telephone. Only the subject and the investigator were present during the interview. All interviews taking place at the University of Montana were recorded on Memorex dBS 60 minute cassette tapes using a Craig voice actuated cassette tape recorder with built in microphone (Model # J109). Telephone interviews were not
recorded.

Professionals were interviewed by the researcher or answered the questionnaire themselves. Data collection involving the professionals took place in their offices at their convenience. All responses from professionals within the Missoula area were recorded on Memorex dBS 60 minute cassette tapes using a Craig voice actuated cassette tape recorder with built in microphone (Model #J109). Responses from professionals outside the Missoula area were recorded on the questionnaire by the professional.

The Child and the Care-giver. Children and their primary care-givers were interviewed separately on the same day by the clinician.

Each care-giver was interviewed first. The interview began with the questions from Form B in an effort to determine how much and what kind of information the care-giver had regarding the child's cleft condition and treatment. At the conclusion of the interview, the investigator answered any questions about the interview procedure.

The child was interviewed in the same room immediately following the care-giver's interview. The investigator first talked with the child until the child appeared comfortable. The child was asked questions from Form A in an effort to determine how much and what kind of information the child had regarding his/her cleft and its treatment. If
the child gave no response or responses such as "I don't know," the investigator used probe statements such as "See if you can guess." If the child answered "I don't know" again, the answer was accepted as fact and the interview continued. Following the interview the clinician answered any questions about the interview procedure. Telephone interviews were conducted in the same manner.

The Professionals. The investigator interviewed four professionals involved with the Comprehensive Development Center's cleft palate clinic. They were: one social worker, one plastic surgeon, one orthodontist, and one speech pathologist. All professionals were asked to respond to the questions dealing with a child's need for information regarding a cleft and its treatment, as well as questions related to each professional's respective field of practice.

Scoring

The responses of the care-givers and the children were compared in an attempt to estimate whether they shared the same base of knowledge about the cleft condition and its treatment. Qualitative analyses of these questions were made. Construction of the 3x3 tables reflected a comparison of the responses of care-giver and child.

The responses of the children and the professionals were also compared. A descriptive analysis was used to estimate the amount of knowledge the child had compared with the amount of information the professionals felt they should
have.

Areas of disagreement between parents and children is discussed and illustrated in tables in Chapter 3. Agreement and disagreement on all questions is available in Appendix C.

Reliability

Both interobserver and intraobserver reliability were obtained by determining the percentage of point by point agreement on scoring responses.

Interobserver reliability was established between the investigator and a graduate student in speech/language pathology at the University of Montana. The recorded responses of 20% of the subjects (randomly selected) were scored by the investigator and the graduate student. The percent agreement was then computed between the two individuals. A point-by-point reliability procedure was used ($\text{agreements} / (\text{agreements} + \text{disagreements}) \times 100$).

Reliability of response within the questionnaire was established by double checks in the form of repeating a question in a slightly reworded fashion. These double checks were installed within all three questionnaires. If a difference existed between an original question and its double check, another version of the question would be asked. If differences existed on more than two different occasions, that subject's responses were not be included in the study.
Chapter III

RESULTS

The purpose of this study was to determine if children with cleft lip and/or palate and their care-givers who receive services in a non-hospital cleft palate clinic setting in Montana share the same information regarding cleft lip and/or palate and its treatment. This chapter will be divided into three sections. The first section will describe the participants in the study. The second section will describe overall trends of disagreement between the children and their care-givers on the first 83 questions of the questionnaire. Areas to be discussed will be a) why families attended the clinic and the professionals seen, b) the number of operations the child has had, c) what Pressure Equalizing (PE) tubes were used for, d) information sources regarding the cleft condition and its treatment, e) future surgery, and f) social aspects of having a cleft condition. These results will be discussed with regard to children only, care-givers only, and children and care-givers combined. Areas of agreement and disagreement collapsed across all dyads for each question will be shown in tables within the text. Agreement and disagreement on all questions for each dyad are available in Appendix C. The last section will discuss the results of the questions designed to elicit descriptive responses. These results
will be discussed with regard to children only, care-givers only, and professionals only.

**Subject Description**

Requests for participation were distributed to approximately 60 families. Thirteen families agreed to participate in this study. The response rate was approximately 22%. One family was excluded because the child had a major disability that would have prohibited him/her from responding to the questions. Two families failed to keep the appointments that were set up.

The care-giver in each family was either the child's mother or father. Nine mothers responded and one father.

The children ranged in age from 6:1 to 18:2. Seven of the children were male and three were female. Eight children had cleft lip and palate, one had cleft lip only, and one had cleft palate only. The characteristics of the children are presented in Table 1.

Four professionals volunteered to participate in this study. The professionals consisted of a plastic surgeon, an orthodontist, a speech therapist, and a social worker. All professionals were members of the Comprehensive Development Center's Cleft Palate Clinic with the exception of the social worker. The social worker that agreed to participate in this study worked with chronically ill children and their families at Community Hospital in Missoula, Montana.
Table 1. Breakdown of Children by Sex, Age, Grade, and Cleft condition.

<table>
<thead>
<tr>
<th>SEX</th>
<th>AGE</th>
<th>GRADE</th>
<th>CLEFT LIP</th>
<th>CLEFT PALATE</th>
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<td>6.11</td>
<td>1st</td>
<td>X</td>
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<tr>
<td>male</td>
<td>9.00</td>
<td>3rd</td>
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<td>male</td>
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<tr>
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<tr>
<td>male</td>
<td>18.20</td>
<td>12+</td>
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</table>

Note. 'X' denotes presence of cleft condition.
In summary, ten children and ten care-givers participated in this study. The children ranged in age from 6 to 18 years and seven were male, three female. Nine mothers and one father comprised the care-givers. Four professionals; a plastic surgeon, an orthodontist, a speech therapist, and a social worker, volunteered to participate in this study.

Overall Trends

Trends of discrepancy in knowledge regarding a cleft and its treatment were arrived at by looking at the percentage of agreement versus disagreement between the parents and the children. If total disagreement between parents and children was 40% or greater it was considered to represent a trend of discrepancy of knowledge which merited further consideration. Table 2 illustrates the total percentage of agreement/disagreement for each question.

One area indicating disagreement between parents and children was why the families attended the cleft palate clinics and what professionals were seen there. As can be seen in Table 2 (questions 7, 8, 9, 10), most families agreed that they attended the clinic because of the cleft condition, but disagreement was indicated with regard to whether the families attended because of concern about speech, dental/orthodontic aspects, or middle ear problems. In all three cases, parents indicated that they attended the
Table 2. Percentages of Agreement/Disagreement between Children and Care-givers Concerning Cleft Lip and/or Palate and Its Treatment.

<table>
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<th>Question #</th>
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<td>Agree</td>
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clinic because of concern about these areas, and the children either disagreed or did not know.

Table 2 (questions 3, 4, 5, 6) illustrates that most parents and children agreed that they saw a surgeon and an orthodontist at the clinic, but there was disagreement about seeing a speech therapist or social worker. In the case of the speech therapist, parents indicated that this professional was seen, and 40% of the children disagreed. Parents indicated that a social worker was seen as well; however, 50% of the children did not know whether they saw a social worker or not.

Another area of discrepancy appeared between parents and children when questioned about the number of operations each child had had (excluding myringotomies). Eight of the ten children disagreed with their parents. In six of the eight cases the child reported having more operations than the parent (Table 2, question 19).

General agreement was noted when the participants were asked if the child had ever had Pressure Equalizing (PE) tubes. However, when asked what the PE tubes were used for the children disagreed with the parents about whether the tubes helped the child hear better and/or helped the ears drain (Table 2, questions 43, 44, 45).

Table 2 (questions 14-17, 22-23, 33, 35-37, 51, 52) shows the percentages of disagreement regarding who provided the families with information about treatment of the cleft
condition. There was little or no agreement between parents and children with regard to whether a speech therapist, social worker, or other individual provided any information about past/present surgery or dental/orthodontic work.

Disagreement was noted with regard to the need for future surgery. In this case more parents than children indicated a need for future surgery (Table 2, question 27).

Questions regarding differences in the social interactions of children with cleft lip and/or palate revealed little agreement. As shown in Table 2 (question 58) 5 of the children reported being treated differently by peers because of the cleft. In only 3 of these cases was the parent aware of this treatment. Two of the parents reported that their child was not treated differently because of the cleft. Five of the children reported no differential treatment by peers. In only three of these cases did the parent agree with the child. Two of the parents reported that the child was treated differently because of the cleft condition.

In summary, disagreement was found between children and their parents regarding reasons the families attended the cleft palate clinic and which professionals they saw, as well as who provided the children and parents with information. Discrepancies were found between parents and children with regard to the number of operations each child had had, and why PE tubes are used. The social aspects
involved with having a cleft lip and/or palate also revealed disagreement between the parents and children.

Parents and children agreed about having a cleft lip and/or palate and whether or not there was still something wrong with the lip and/or palate. Agreement was indicated with regard to what may have caused the cleft and if it was hereditary or not. Eighty percent of the children agreed with their parents with regard to having had surgery to the lip or palate or whether they had ever had PE tubes. Sixty percent of the children agreed with their parents with regard to the surgeon providing most of the information about future surgery. Eight families agreed that the orthodontist provided the most information with regard to dental/orthodontic work. Total agreement was found concerning dental/orthodontic work that had been done.

The responses to the questions asked of the children and the care-givers indicated that there were approximately as many areas of agreement as areas of disagreement. The present study would indicate that children and care-givers do not share the same knowledge about cleft palate and its treatment.

Descriptive Analysis

The same questions addressed in the first part of the questionnaires were condensed into 15 open-ended, probe questions and asked again allowing the participants to
answer in their own words rather than with the "Yes, No, I don't know" format. These responses were examined to determine the extent of knowledge each participant had and areas of discrepancy between children and care-givers, and the possible reasons behind the discrepancies.

Children The children in this study (with the exception of the two youngest) exhibited correct knowledge of what a cleft lip and/or palate was, aspects of future surgery, and the relationship between speech and a cleft condition. Most of the children indicated that the reason they attended the cleft palate clinic was to get advice about what step to take next and to see how the previous surgeries had worked. Many of the children indicated that they were teased by peers because of the way they looked or the way they talked. All the children expressed a desire to know more about future plans for taking care of the cleft and half of the children would like to know more with regard to whether or not their children would have clefts. Every child indicated that they talked with their parents about the cleft and its treatment.

Discrepancies between children and care-givers occurred with regard to past surgeries and what the past surgeries were for. The children were either unable to describe past surgeries and the reasons, or they were able to give only a very brief description of what they thought had happened and what the surgeries may have been for.
Another area of discrepancy occurred between children and parents with regard to the social interactions of the children. The children were able to describe the treatment they received from other children because of their cleft condition whereas the parents could not.

Parents The parents participating in this study demonstrated knowledge regarding their child's cleft condition. They indicated that the reasons for attending the cleft palate clinics ranged from being referred by someone, looking for suggestions, to being able to see the right professionals and getting the right information. All parents were able to describe a cleft lip and cleft palate, what past surgeries were for, what future surgeries were for, and the relationship between speech and a cleft condition. Several parents wished they had had more specific information with regard to past surgeries and treatments, but were satisfied with the information they received. Parents indicated that they would like to know more about the future for their child regarding the cleft condition. All the parents indicated that the professionals involved with the cleft palate clinic were "great" about letting them know what the next step would be and were "extremely helpful".

Discrepancies occurred between parents and children with regard to past surgeries and the reasons for the past surgeries. All parents were able to describe each past
surgery and the reason behind the surgeries.

Another area of discrepancy occurred regarding the children's social interactions. The parents did not exhibit knowledge about the treatment the children received because of their cleft lip and/or palate.

Professionals All professionals interviewed indicated that they thought it was important for the child to know about the cleft condition and its treatment. However, they indicated that the extent of the knowledge was age dependent and that they often waited for the children to ask questions before discussing past surgeries, procedural aspects of surgery, and the hereditary aspects of the cleft condition. Each professional indicated that they frequently asked the children and parents if they had any questions. All professionals indicated that care-givers should provide the children with information about the cleft and treatment, to the extent of the care-giver's understanding. However, all professionals reported that not many care-givers were capable of providing the appropriate information.

In summary, the descriptive responses indicated that discrepancies were evident between parents and children regarding past surgeries. Discrepancies between parents and children were also noted with regard to the social interactions of children with cleft lip and/or palate. Interviews with the professionals revealed that they do not talk with the children about past surgeries, nor do they
talk about the social interactions of children with cleft conditions.

Interobserver and intraobserver reliability using a point-by-point procedure both revealed 100% agreement. Problems of reliability within the questionnaire did not occur; therefore, no subjects were excluded from this study.

A discussion of the results and limitations of the study are presented next. In addition, suggestions for future research are made.
Chapter IV
Discussion

This study investigated the agreement/disagreement between children with cleft lip and/or palate and their parents on issues regarding the cleft condition and its treatment. Disagreements were noted in six areas; however, the meaningfulness of these disagreements must be questioned. First, this sample cannot be generalized to the total cleft lip and/or palate population because of its small size. The type of information obtained in this study could not be statistically analyzed; therefore, significance could not be determined in the cases of disagreement. Each area of disagreement will be discussed with its limitations in the following paragraphs.

Information About Attending the Cleft Palate Clinic and the Professionals Seen

Although disagreement existed between parents and children with regard to seeing a speech therapist and social worker at the clinic, caution must be taken when considering this information. Two of the four children in disagreement with their parents about seeing a speech therapist did not have a cleft lip and palate. One child had a unilateral cleft of the lip, the other had a cleft of the soft palate. Neither had ever had any speech problems or therapy. Speech
problems may not have been a concern or emphasized for these families. Therefore, only two children who had received speech therapy disagreed with their parents over seeing a speech therapist. Disagreement over seeing a social worker must be discounted completely because the Comprehensive Development Center does not employ a social worker for the cleft palate clinics. These results may have been influenced if the children were seeing the surgeon and the orthodontist more frequently outside of the clinic than the other professionals. These results may also have been influenced if the children were seeing the surgeon and orthodontist outside the clinic but not seeing the other professionals outside the clinic, as is the case with the CDC cleft palate clinics. The children may have come to know the surgeon and orthodontist because of the frequency of visits or because of the invasive nature of the work done by a surgeon or orthodontist.

Disagreement with regard to why the families attended the cleft palate clinic was contrary to findings by Walesky-Rainbow and Morris (1978). Walesky-Rainbow and Morris (1978) found that children and care-givers were aware of the reasons for attending the cleft palate clinic. The results of the questions asked in the present study indicated that the children were not aware of all the reasons for attending the clinic. These results may have been influenced by professionals not identifying themselves or what they were
evaluating. Possibly parents did not reveal exactly why the family was attending the cleft palate clinic.

It is evident from the results in these two areas that more time needs to be taken to explain to the children who each professionals is in order to increase the childs' understanding of why the family is attending the cleft palate clinic and who they are seeing. Each professional should introduce himself/herself to each child and explain what they are evaluating.

Number of Operations (excluding myringotomies)

Disagreement was found between parents and children about how many operations the child had had. In most cases the child reported having more operations than what the parent reported. These results may have occurred because the children were too young to remember the first surgeries and the reason for the surgeries. Without some references to the reasons behind the surgeries, it is possible that an individual would not know the exact number of surgeries they have undergone. Responses of children, parents, and professionals to questions about past surgery indicated that the surgeon as well as the parents did not tend to discuss past surgeries; therefore, children would not have information about the surgeries. Parents would have a better idea of how many surgeries children had had because they may have known the reason for each surgery.
Pressure Equalizing (PE) Tubes

Agreement was revealed with regard to whether the child had had PE tubes; however, the reasons for using tubes presented disagreement. This study revealed that professionals did not tend to discuss past surgeries and PE tubes may have been inserted when the children were very young; therefore, the children may not have been made aware of the reasons for using PE tubes. Walesky-Rainbow and Morris (1978) found results similar to the present study indicating that children did not typically know why PE tubes were used.

Information Providers

This study indicated that the child's primary source of information was the care-giver; however, the children were lacking information with regard to why the families attended the cleft palate clinics and which professionals were seen, the number of operations the children had had, the reason for using PE tubes, and social aspects. It appeared that neither the parents nor the professionals were making sure the children knew who they were seeing or why. It also appeared that no one was telling the children about past surgeries and the need for them. The parents may have been assuming that the children knew the professionals they were seeing and why. The parents may also have assumed that the children did not need information concerning past surgeries.
The surgeon provided information about future surgery and some dental/orthodontic aspects. The orthodontist provided information about the dental/orthodontic work. These results were found in the Walesky-Rainbow and Morris (1978) study in which professionals indicated that they did not provide information about past surgery, nor did they provide information about areas other than their own. Most of the children indicated that they were too young to remember past surgery or who provided the information. This must be considered when analyzing this information.

The rural setting of this study may have influenced who provided the child with information. It may have been that the children in a rural setting do not see the professionals as frequently as children in a more metropolitan area. In this kind of situation parents may be expected to or feel compelled to provide their child with information about the cleft and its treatment.

Future Surgery

Disagreement was noted with regard to the need for future surgery; however, this may have been influenced by the number of children who considered any future surgery as optional. These children indicated that any future surgery was their decision and was not mandatory. Many reported that future surgery was cosmetic, "if I don't like the way I look". The parents were more inclined to say that the
surgery was needed or "I think he should have the surgery, but the decision is up to him."

Social Aspects

Very little agreement was found between the parents and children with regard to social the aspects of having a cleft lip and/or palate. Results indicated that some children were being treated differently by their peers while their parents were unaware of it. Most of the children were unaware of the effect their cleft condition had on their care-giver or siblings. This disagreement may have been influenced by the care-giver not knowing that peer treatment may have an effect on children. The children may not be mentioning any ill-treatment or effects the treatment may have. Parents, on the other hand, may not be mentioning the effects the child's cleft condition may be having on the family. The families in this study may not have been discussing openly the monetary or jealousy affects that may be involved, and were mentioned by individual dyads, when a child has a cleft lip and/or palate.

In summary, although disagreements were noted with regard to why families attend the cleft palate clinic and who they see, the number of operations the children had undergone, the reasons for using PE tubes, who provided information, and the need for future surgery, several reasons for the disagreements have been noted as well.
Children may have had more information about seeing a surgeon or orthodontist because of the invasiveness of their work and because they may have been seeing the same surgeon and orthodontist outside of the clinic. The disagreement between parents and children over the number of operations may have been influenced by the children being too young to remember the surgeries and the professionals and parents not discussing past surgeries. Disagreement between children and parents with regard to future surgery may have been influenced by the number of children who considered any future surgery as optional.

Descriptive Analysis

Children The children in this study exhibited knowledge in many aspects of a cleft and its treatment. However, most of the children indicated that they were or had been teased by other children about the cleft. Possibly these children did not feel comfortable talking about their feeling with their parents or other professionals. It could be that if a social worker were available these children may have been more able to deal with the ill-treatment.

More time needs to be spent with the children discussing future plans for taking care of the cleft. All the children in this study indicated a desire to know more in this area.

Half of the children expressed a desire to know whether
their children would have clefts. Possibly the explanations about the etiology and hereditary aspects had not been explained in enough detail to satisfy the need for this knowledge. A social worker or clinic coordinator may be beneficial in making sure children are getting the information they need and want.

**Parents** Parents participating in this study indicated a desire to know more about future plans for their child's cleft condition and treatment. Most parents indicated that the professionals made them aware of the treatment being a "one step at a time" process; however, it may have been that the parents needed more information about the future even if the information was not specific. It may be that the parents would benefit from having a social worker or clinic coordinator making sure the information needed and/or wanted is being provided.

**Professionals** The professionals interviewed indicated that they did not make a practice of discussing past surgeries. The children in this study indicated a lack of understanding in the area of past surgeries and may have had a better understanding of the cleft and treatment if they had had more information about the past. The professionals also indicated that they did not discuss the hereditary aspects of the cleft. The children expressed a desire to know more in this area as well.

In summary, this study revealed that children were
receiving most of their information from the care-giver and that the information they were receiving was accurate. However, results indicated that 50% of the knowledge is shared and tends to be information regarding what the problem is. Fifty percent of the information is unshared and appears to be the effects of the problem, what has been and should be done about the problem, and how the work is done. This would indicate that the hypothesis of this study was true, parents and children do not share the same body of knowledge. Parents and children share half of the information requested in this study. Some important areas of information appeared to be missing, possibly because the parents did not discuss it with the children or did not realize the child's need for such information, or the professionals were not taking the time to discuss these aspects with the children. It may be that the care-givers who participated in this study were biased, in that they volunteered to take part in this study because of a desire to help improve services for all families with a child with a cleft condition. The bias may have influenced the amount of agreement found in this study because people who volunteer often make an effort to know more. However, the bias does not explain why there were areas of information missing for the children. It may be that had the professionals been provided with the information that the parents were giving the children more information could have
been obtained which compared what the professionals thought they were telling parents and what parents thought they were telling their children. Throughout this study the children tended to disagree more with the parents, however, no one dyad contributed more to the disagreements. It appears that both parents and children would benefit from the services of a social worker or clinic coordinator who made sure that the families were getting information.

It appears from comparing the results of this study with the results of the Spriestersbach (1973) study and the Walesky-Rainbow and Morris (1978) study that receiving services in a hospital setting versus a non-hospital setting is similar. The children in each of these studies were lacking knowledge about the cleft and its treatment. Walesky-Rainbow and Morris indicated that the children in their study lacked knowledge regarding what a cleft is, future surgery, etiology of a cleft, and the relationship between a cleft and speech. Spriestersbach (1973) concluded that the children in his study lacked knowledge regarding past surgeries and the reasons for them. The present study revealed that children lacked knowledge regarding the reasons for attending the Cleft Palate Clinics, the professionals seen, the number of operations the child had had, the reasons for using PE tubes, information providers, and the social aspects of having a cleft.
Even though children are lacking some information regarding the cleft and its treatment the present study revealed that the children involved knew about what the cleft was, the etiology, future surgical aspects, and the relationship between speech and a cleft condition. As mentioned in Chapter 1, researchers believe the main goal of counseling is to provide information. Bricklin (1970) indicated that children need to know about the disorder, the etiology, and the prognosis. The children involved in the present study exhibited much of the knowledge researchers suggest is important to acceptance of and adjustment to their cleft condition. It may not be so important who is providing this information as it is that the children are receiving the information. The present study indicated that the children were not getting the information from the professionals, but from their care-givers.

Limitations of the Study

One limitation of this study was that the number of participants was so small that a statistical analysis could not be made to determine significant disagreement between care-giver and child. If the sample size had been larger the results might have been more powerful and could have been more easily applied to a larger population of children with cleft lip and/or palate.

The size of the sample also limited the researcher from
drawing any conclusions with regard to age and type of cleft. Had more families been involved a difference in amount and extent of information may have been revealed between younger children and their parents and the older children and their parents. More families may have limited any bias as well. Differences may also have been found with relation to the type of cleft and the amount of agreement between parent and child.

The return rate for this study was approximately 20%. One must be aware that the group interviewed may have been biased, in that these families may have had a desire to do all they can to help other families with children with cleft conditions. Therefore, the volunteer families would know more, and inform the children more, leading to more agreement.

The number of professionals interviewed may have limited this study. With only one professional interviewed in each area, only one opinion was given. Other professionals working with the same population of children and parents may have had different ideas on counseling.

The types of interviews were limiting. Each interview should be conducted in person to allow the researcher to establish a rapport with the families. The six interviews conducted on the telephone may have influenced the amount of information the participants were revealing.
Further Research

A replication of this study with certain modifications seems warranted. Such replication should include a much larger number of subjects. An effort should be made to control for age and cleft type so that enough subjects are in each group to make the sample representative of a larger population.

Less emphasis should be placed on past surgeries, as this seems to be an area of confusion for the children because they were so young at the time of the major surgeries. However, more questions should be asked with regard to future surgery and what the child wishes to know with regard to the cleft and its treatment.

A study done using only the professionals children are likely to see on a regular basis may be more beneficial. The children participating in this study had not been seeing a social worker; therefore, questions regarding a social worker were not relevant to this study.

More emphasis should be placed on information-sharing between professionals and parents. It may be important for professionals to know the information the parents have and are sharing with their children. This information sharing could lead to better counseling services by the professionals.

A sequel done in this manner may allow for better assessment of the effectiveness of the counseling being
done. The researcher may then be able to draw significant conclusions with regard to the effectiveness of counseling of the child with a cleft lip and/or palate and their parents.
The present study examined the knowledge base of children with cleft lip and/or palate and their parents who received services at a non-hospital cleft palate clinic. The results of the study indicated that parents and children share approximately 50% of the knowledge requested in this study. The areas of unshared information include the reasons for attending the cleft palate clinic and which professionals are seen, the number of operations the child has had, the reasons for inserting PE tubes, information providers, and social aspects of having a cleft lip and/or palate. Even though children are lacking information about their cleft condition and its treatment, past research suggests that they are receiving much of the information needed for acceptance of and adjustment to the cleft condition.

Further research utilizing a larger and more representative sample might produce results more applicable to the general population of children with cleft lip and/or palate.
Appendix A

University of Montana

Information Summary and Consent Form

The purpose of this research study is to determine if children with cleft lip and/or palate and their primary care-givers share the same body of knowledge regarding cleft lip and/or palate and its treatment. Past research in this area has looked at children and their care-givers who receive services in hospital settings. This study is designed to look at the information children and their care-givers receive in a non-hospital cleft palate clinic and compare these results with the results of past studies.

If you agree to participate in this study, you will be asked a series of questions regarding cleft lip and/or palate and its treatment. This interview/questionnaire will take approximately one half hour.

Participation in this study is strictly voluntary. Even if you agree to participate, you are free to withdraw at any time. The results of the study will be kept strictly confidential. Any identifying information will be removed from my research files.

Your participation in this study is greatly appreciated. This study will help us learn more about the information provided and counseling needed for children with cleft lip and/or palate and their care-givers.

I have read the above description of the research study to be conducted by Ms. Jodie Egosque B.A. I understand the procedures and benefits involved in the participation in this study and that there are no risks.

I give my permission for my child ________________________________,
(name)
to participate in this study.

__________________________  ____________________________
Signature of Care-giver     Signature of Child
(Parent or Guardian)

__________________________
Date
Appendix A (cont.)

University of Montana

Information Summary and Consent Form

The purpose of this research study is to determine if children with cleft lip and/or palate and their primary care-givers share the same body of knowledge regarding cleft lip and/or palate and its treatment. Past research in this area has looked at children and their care-givers who receive services in hospital settings. This study is designed to look at the information children and their care-givers receive in a non-hospital cleft palate clinic and compare these results with the results of past studies.

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Participation in this study is strictly voluntary. Even if you agree to participate, you are free to withdraw at any time. The results of the study will be kept strictly confidential. Any identifying information will be removed from my research files.

Your participation in this study is greatly appreciated. This study will help us learn more about the information provided and counseling needed for children with cleft lip and/or palate and their care-givers.

I have read the above description of the research study to be conducted by Ms. Jodie Egosque, B.A. I understand the procedures and benefits involved in the participation in this study and that there are no risks.

I ________________________ , agree to participate in this study.

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Date
Appendix A (cont.)

University of Montana

* * * Basic Consent Form * * *

Certification of Subject Consent By
Legally Authorized Representative

Project Title: ____________________________

Investigator: ____________________________

I, _________________________________, the ____________________________________
(Relationship)
of __________________________________, hereby certify that I
(Child's Name) (Subject) have been informed by Ms. Jodie Egosque B.A. (graduate
student, University of Montana) about participation in a
research study to determine if children with cleft lip
and/or palate and their care-givers share the same body of
knowledge regarding cleft lip/or palate and it's treatment.
I have been informed about the procedures to be followed and
the amount of time involved. I understand there are no risks
to the subject. I have been informed about the possible
benefits from the research. I have also been informed that
the records identifying the subject will be kept strictly
confidential.

A written summary describing the research is attached. I
have been given adequate opportunity to read it.

I understand I have the right to contact Jodie Egosque or
Alice E. Smith at the University of Montana (406-243-4131)
if I have any questions about this research or my rights.

I understand that I have the right to withdraw from this
consent to take part in the project at any time and withdraw
my child from the project without penalty or loss of
benefits to which he/she may be entitled.

I hereby freely consent to ______________________________
(Child's Name)
participate in this project.

(Signature of Parent or Guardian)
Appendix B

Questionnaires

Key: * denotes double checks
     -- denotes question asked only of the child

Form A: General Information About Cleft - Child

1. Do you have a cleft lip?
   Yes____
   No____
   I don't know____

2. Do you have a cleft palate?
   Yes____
   No____
   I don't know____

3. Do you see a surgeon when you come to the clinic?
   Yes____
   No____
   I don't know____

4. Do you see a dentist/orthodontist when you come to the clinic?
   Yes____
   No____
   I don't know____

5. Do you see a speech therapist when you come to the clinic?
   Yes____
   No____
   I don't know____

6. Do you see a social worker when you come to the clinic?
   Yes____
   No____
   I don't know____

7. Do you come to the clinic because of your cleft condition?
   Yes____
   No____
   I don't know____
Appendix B (cont.)

8. Do you come to the clinic because of your teeth?
   Yes
   No
   I don't know

9. Do you come to the clinic because of your speech?
   Yes
   No
   I don't know

10. Do you come to the clinic because of your ears?
    Yes
    No
    I don't know

11. Is there something wrong with your lip now?
    Yes
    No
    I don't know

12. Is there something wrong with your palate now?
    Yes
    No
    I don't know

* Do you see someone about your speech?
  Yes
  No
  I don't know

* Do you see someone about your teeth?
  Yes
  No
  I don't know

* Do you see someone about your lip?
  Yes
  No
  I don't know

* Do you see someone about your palate?
  Yes
  No
  I don't know

13. Do you know what caused your cleft?
    Yes
    No
    I don't know
Appendix B (cont.)

13a. Was your cleft hereditary?
   Yes____
   No____
   I don't know____

13b. Was your cleft related to some accident?
   Yes____
   No____
   I don't know____

14. Did your doctor tell you this?
   Yes____
   No____
   I don't know____

15. Did your dentist/orthodontist tell you this?
   Yes____
   No____
   I don't know____

16. Did your social worker tell you this?
   Yes____
   No____
   I don't know____

17. Did your speech therapist tell you this?
   Yes____
   No____
   I don't know____

-- Did your care-giver tell you this?
   Yes____
   No____
   I don't know____

SURGICAL ASPECTS

18. Did you ever have an operation on your cleft?
   Yes____
   No____
   I don't know____

19. How many operations have you had on your cleft (not including myringotomies)?

20. Was an operation to repair your lip?
   Yes____
   No____
   I don't know____
Appendix B (cont.)

21. Was an operation to repair your palate?  
   Yes____  
   No____  
   I don't know____

22. Did your doctor explain what was to happen while you were in the hospital?  
   Yes____  
   No____  
   I don't know____

23. Did someone else explain what was to happen while you were in the hospital?  
   Yes____ Who?  
   No____  
   I don't know____

   Did your care-giver explain what was to happen while you were in the hospital?  
   Yes____  
   No____  
   I don't know____

24. Were you told the surgery was to repair your lip?  
   Yes____  
   No____  
   I don't know____

25. Were you told the surgery was to repair your palate?  
   Yes____  
   No____  
   I don't know____

26. Were you told the surgery was to help you talk better?  
   Yes____  
   No____  
   I don't know____

* While you were in the hospital, did anyone explain what was to happen?  
   Yes____  
   No____  
   I don't know____

27. Do you need more surgery?  
   Yes____  
   No____  
   I don't know____
Appendix B (cont.)

28. Will more work need to be done on your lip?
   Yes_____  
   No_____    
   I don't know_____ 

29. Will more work need to be done on your palate?
   Yes_____  
   No_____    
   I don't know_____ 

30. Will more work need to be done on your ears?
   Yes_____  
   No_____    
   I don't know_____ 

31. Did your doctor tell you why the work needed to be done?
   Yes_____  
   No_____    
   I don't know_____ 

32. Did the social worker tell you why the work needed to be done?
   Yes_____  
   No_____    
   I don't know_____ 

33. Did your dentist/orthodontist tell you why the work needed to be done?
   Yes_____  
   No_____    
   I don't know_____ 

34. Did someone else tell you why the work needed to be done?
   Yes_____  Who?  
   No_____    
   I don't know_____ 

   Did your care-giver tell you why the work needed to be done?
   Yes_____  
   No_____    
   I don't know_____
Appendix B (cont.)

35. Did your doctor explain what will happen while you are in the hospital?
   Yes____
   No____
   I don't know____

36. Did the social worker explain what will happen while you are in the hospital?
   Yes____
   No____
   I don't know____

37. Did your dentist explain what will happen while you are in the hospital?
   Yes____
   No____
   I don't know____

38. Did someone else explain what will happen while you are in the hospital?
   Yes______ Who?
   No____
   I don't know____

-- Did your care-giver explain what will happen while you are in the hospital?
   Yes____
   No____
   I don't know____

39. Were you told the future surgery was for your lip?
   Yes____
   No____
   I don't know____

40. Were you told the future surgery was for your palate?
   Yes____
   No____
   I don't know____

41. Were you told the future surgery was to help you talk better?
   Yes____
   No____
   I don't know____

42. Were you told the future surgery was for your ears?
   Yes____
   No____
   I don't know____
Appendix B (cont.)

43. Do/did you have Pressure Equalizing (PE) tubes in your ears?
   Yes____
   No____
   I don't know____

44. Are they used to help you hear better?
   Yes____
   No____
   I don't know____

45. Are they used to help your ears drain?
   Yes____
   No____
   I don't know____

DENTAL/ORTHODONTIC ASPECTS

46. Have you ever had any dental/orthodontic work done?
   Yes____
   No____
   I don't know____

47. Was the work done for your teeth?
   Yes____
   No____
   I don't know____

48. Was the work done for your palate?
   Yes____
   No____
   I don't know____

49. Did your dentist/orthodontist explain this to you?
   Yes____
   No____
   I don't know____

50. Did the social worker explain this to you?
   Yes____
   No____
   I don't know____

51. Did your doctor explain this to you?
   Yes____
   No____
   I don't know____
Appendix B (cont.)

52. Did someone else explain this to you?
  Yes____  Who?
  No____
  I don't know____

-- Did your care-giver explain this to you?
  Yes____
  No____
  I don't know____

SPEECH ASPECTS

53. Have you ever had any special work on your speech?
  Yes____
  No____
  I don't know____

54. Is the speech work to help you not talk through your nose?
  Yes____
  No____
  I don't know____

55. Is the speech work to help you say sounds more clearly?
  Yes____
  No____
  I don't know____

56. Do you think this speech work helps you?
  Yes____
  No____
  I don't know____

SOCIAL ASPECTS

57. Do/did adults treat you differently because of your cleft?
  Yes____
  No____
  I don't know____

58. Do/did other children treat you differently because of your cleft?
  Yes____
  No____
  I don't know____
Appendix B (cont.)

59. Do you think your cleft effects your parents?
   Yes____
   No____
   I don't know____

60. Do you think your cleft effects your brothers or sisters?
   Yes____
   No____
   I don't know____

DESCRIPTIVE QUESTIONS

1. Why do you come to the clinic?
2. What is a cleft lip?
3. What is a cleft palate?
4. What was past surgery for?
5. What were you told about what would happen while you were in the hospital?
6. Why do you need more surgery?
7. What were you told would happen with regard to future surgery?
8. Why would you have tubes in your ears?
9. Why was dental work needed?
10. Why are you receiving speech therapy?
11. What does talking have to do with a cleft lip and/or palate?
12. How does speech therapy help your speech?
13. How are you treated differently from others with regard to your cleft?
14. Who treats you differently?
15. How does your cleft condition effect your family?
Appendix B (cont.)

CARE-GIVER ASPECTS

1. Did your care-giver ever talk to you about your cleft?
2. Did you understand what they told you?
3. Did you ever ask them about your cleft?
4. Do you wish you knew more about the future plans for taking care of your cleft?
5. Does anyone (care-giver or clinic staff) ever ask you if you have any questions about what is going on with regard to your cleft?
6. Do you think that there is a possibility that any of your children may have clefts?

* Have you ever asked your care-giver anything about your cleft?
Form B: General Information About Cleft - Care-giver

1. Does your child have a cleft lip?
   Yes____
   No____
   I don't know____

2. Does your child have a cleft palate?
   Yes____
   No____
   I don't know____

3. Does your child see a surgeon when you come to the clinic?
   Yes____
   No____
   I don't know____

4. Does your child see a dentist/orthodontist when you come to the clinic?
   Yes____
   No____
   I don't know____

5. Does your child see a speech therapist when you come to the clinic?
   Yes____
   No____
   I don't know____

6. Does your child see a social worker when you come to the clinic?
   Yes____
   No____
   I don't know____

7. Does your child come to the clinic because of a cleft condition?
   Yes____
   No____
   I don't know____

8. Does your child come to the clinic because of his/her teeth?
   Yes____
   No____
   I don't know____
Appendix B (cont.)

9. Does your child come to the clinic because of his/her speech?
   Yes____
   No____
   I don't know____

10. Does your child come to the clinic because of his/her ears?
    Yes____
    No____
    I don't know____

11. Is there something wrong with your child's lip now?
    Yes____
    No____
    I don't know____

12. Is there something wrong with your child's palate now?
    Yes____
    No____
    I don't know____

* Does your child see someone about his/her speech?
   Yes____
   No____
   I don't know____

* Does your child see someone about his/her teeth?
   Yes____
   No____
   I don't know____

* Does your child see someone about his/her lip?
   Yes____
   No____
   I don't know____

* Does your child see someone about his/her palate?
   Yes____
   No____
   I don't know____

13. Do you know what caused your child's cleft?
    Yes____
    No____
    I don't know____
Appendix B (cont.)

13a. Was your child's cleft hereditary?
   Yes____
   No____
   I don't know____

13b. Was your child's cleft related to some accident?
   Yes____
   No____
   I don't know____

14. Did the doctor tell you this?
   Yes____
   No____
   I don't know____

15. Did the dentist/orthodontist tell you this?
   Yes____
   No____
   I don't know____

16. Did the social worker tell you this?
   Yes____
   No____
   I don't know____

17. Did your speech therapist tell you this?
   Yes____
   No____
   I don't know____

SURGICAL ASPECTS

18. Did your child ever have an operation on his/her cleft?
   Yes____
   No____
   I don't know____

19. How many operations has your child had on his/her cleft (not including myringotomies)?

20. Was an operation to repair your child's lip?
   Yes____
   No____
   I don't know____

21. Was an operation to repair your child's palate?
   Yes____
   No____
   I don't know____
Appendix B (cont.)

22. Did the doctor explain what was to happen while your child was in the hospital?
   Yes
   No
   I don't know

23. Did someone else explain what was to happen while your child was in the hospital?
   Yes Who?
   No
   I don't know

24. Were you told the surgery was to repair your child's lip?
   Yes
   No
   I don't know

25. Were you told the surgery was to repair your child's palate?
   Yes
   No
   I don't know

26. Were you told the surgery was to help your child talk better?
   Yes
   No
   I don't know

* While your child was in the hospital, did anyone explain what was to happen?
   Yes
   No
   I don't know

27. Does your child need more surgery?
   Yes
   No
   I don't know

28. Will more work need to be done on the lip?
   Yes
   No
   I don't know

29. Will more work need to be done on the palate?
   Yes
   No
   I don't know
Appendix B (cont.)

30. Will work need to be done on the ears?
   Yes____
   No____
   I don't know____

31. Did the doctor tell you why the work needed to be done?
   Yes____
   No____
   I don't know____

32. Did the social worker tell you why the work needed to be done?
   Yes____
   No____
   I don't know____

33. Did the dentist/orthodontist tell you why the work needed to be done?
   Yes____
   No____
   I don't know____

34. Did someone else tell you why the work needed to be done?
   Yes____ Who?
   No____
   I don't know____

35. Did the doctor what will happen while your child is in the hospital?
   Yes____
   No____
   I don't know____

36. Did the social worker explain what will happen while your child is in the hospital?
   Yes____
   No____
   I don't know____

37. Did your dentist/orthodontist explain what will happen while your child is in the hospital?
   Yes____
   No____
   I don't know____
Appendix B (cont.)

38. Did someone else explain what will happen while your child is in the hospital?
   Yes______ Who?
   No______
   I don't know______

39. Were you told the future surgery was for the lip?
   Yes______
   No______
   I don't know______

40. Were you told the future surgery was for the palate?
   Yes______
   No______
   I don't know______

41. Were you told the future surgery was to help your child talk better?
   Yes______
   No______
   I don't know______

42. Were you told the future surgery was for the ears?
   Yes______
   No______
   I don't know______

43. Does/did your child have Pressure Equalizing (PE) tubes in his/her ears?
   Yes______
   No______
   I don't know______

44. Are they used to help your child hear better?
   Yes______
   No______
   I don't know______

45. Are they used to help your child's ears drain?
   Yes______
   No______
   I don't know______

DENTAL/ORTHODONTIC ASPECTS

46. Has your child had any dental/orthodontic work done?
   Yes______
   No______
   I don't know______
Appendix B (cont.)

47. Was the work done for the teeth?
   Yes____
   No____
   I don't know____

48. Was the work done for the palate?
   Yes____
   No____
   I don't know____

49. Did the dentist/orthodontist explain this to you?
   Yes____
   No____
   I don't know____

50. Did the social worker explain this to you?
   Yes____
   No____
   I don't know____

51. Did the doctor explain this to you?
   Yes____
   No____
   I don't know____

52. Did someone else explain this to you?
   Yes____ Who?
   No____
   I don't know____

SPEECH ASPECTS

53. Has your child ever had any special work on his/her speech?
   Yes____
   No____
   I don't know____

54. Is the speech work to help your child not talk through his/her nose?
   Yes____
   No____
   I don't know____

55. Is the speech work to help your child say sounds more clearly?
   Yes____
   No____
   I don't know____
Appendix B (cont.)

56. Do you think this speech work helps your child?
   Yes____
   No____
   I don't know____

SOCIAL ASPECTS

57. Do/did adults treat your child differently because of the cleft?
   Yes____
   No____
   I don't know____

58. Do/did other children treat your child differently because of the cleft?
   Yes____
   No____
   I don't know____

59. Does your child's cleft effect you, as a care-giver?
   Yes____
   No____
   I don't know____

60. Does your child's cleft effect his/her brothers or sisters?
   Yes____
   No____
   I don't know____

DESCRIPTIVE QUESTIONS

1. Why does your child come to this clinic?
2. What is a cleft lip?
3. What is a cleft palate?
4. What was past surgery for?
5. What were you told about what would happen while your child was in the hospital?
6. Why does your child need more surgery?
7. What were you told would happen with regard to future surgery?
Appendix B (cont.)

8. Why would your child have tubes in his/her ears?
9. Why did your child need dental work?
10. Why is your child receiving speech therapy?
11. What does talking have to do with a cleft lip and/or palate?
12. How does speech therapy help your child's speech?
13. How is your child treated differently from others with regard to his/her cleft?
14. Who treats your child differently?
15. How does your child's cleft condition effect your family?

CARE-GIVER ASPECTS

1. Does your child ever talk to you about his/her cleft?
2. Does your child ever ask you questions about his/her cleft?
3. Do you wish you knew more about the future plans with regard to your child's cleft?
4. Does anyone on the clinic staff ever ask you if you have any questions about what's going on with regard to your child's cleft?
5. Do you think that there is a possibility that any of your child's children may have clefts?
Appendix B (cont.)

Form C: Professionals

1. Should the child know he has a cleft lip and/or palate?

2. Should the care-giver know the child has a cleft lip and/or palate?

3. Should the child know that he comes to the clinic for treatment of the cleft?

4. Should the care-giver know that the child comes to the clinic for treatment of the cleft?

5. What members of the clinic staff should the child know he sees?

6. What members of the clinic staff should the care-giver know the child sees?

7. What kind of layman's description should the child know regarding the cleft condition?

8. What kind of layman's description should the care-giver know regarding the cleft condition?

9. How much should the child know about what caused the cleft?

10. How much should the care-giver know about what caused the cleft?

11. How much should the child know about the possibility of his/her children having clefts?

12. How much should the care-giver know about the possibility of their child's children having clefts?

13. Do you routinely ask your patients with clefts if they have any questions?

14. Do you routinely ask the care-givers if they have any questions?

15. What do you think the child should know about his/her cleft condition?

16. What do you think the care-giver should know about the child's cleft condition?
Appendix B (cont.)

* Is it important for the child to know he/she has a cleft?

* Is it important for the care-giver to know his/her child has a cleft?

17. How much information do you encourage care-givers to provide the child?

18. Do you think the care-giver can effectively provide accurate and sufficient information to the child?

SURGICAL ASPECTS

1. Should the child know that he/she has had surgery for his/her cleft?

2. Do you routinely explain to the child what past surgery was for?

3. What do you routinely tell the child about future surgery?

4. Should the child know if he has ever had PE tubes?

5. What do you routinely tell the child regarding tubes?

DENTAL ASPECTS

1. Should the child know he/she is/was having dental work done?

2. Should the child know what dental work is being done?

3. Should the child know why?

4. How much about possible outcomes should the child know?

5. What do you routinely tell the child regarding dental work?

SPEECH ASPECTS

1. Should the child know whether or not he/she ever worked on his/her speech?
Appendix B (cont.)

2. Should the child know that he/she works/worked on his/her speech to improve it? How much should they know?

3. Should the child know that an open cleft results in nasal speech? How much should they know?

4. How much of the possible outcomes should the child know?

5. What do you routinely tell a child about speech therapy?

SOCIAL ASPECTS

1. Should the child know the social implications involved in having a cleft? How much should they know?

2. Should the child know the financial implications with having a cleft? How much should they know?

3. How much should the child know about the effects having a cleft may have on other family members?

4. What do you routinely tell a child with a cleft condition?
Appendix C

Agreement/Disagreement for Individual Dyads

Dyad #1

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REFERENCES


References (cont.)

