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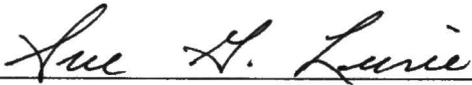
Schimmoller, Mary V. Education of Parents of Newborns with Cleft Lip/Cleft Palate by Healthcare Professionals in Texas Hospitals. Master of Public Health (Community Health), May 2005, 37 pp., references, 22 titles.

The purpose of this study was to ascertain what, how, when and by whom information is given to parents of cleft lip/palate newborns in Texas hospitals and whether additional information is needed. Methods: Telephone interviews with 97 health care professionals who provide initial care to moms of cleft lip/palate newborns in the 159 Texas hospitals with more than 500 live births in 2003/2004. Findings: 76% of respondents said information given to parents of cleft newborns is effective/ very effective, 63% gave conflicting responses on whether babies with cleft can breastfeed, 35% said additional information is needed, 7% said they need information in additional languages. Conclusion: Information given to parents with cleft lip/palate newborns in Texas hospitals is inconsistent and often insufficient.

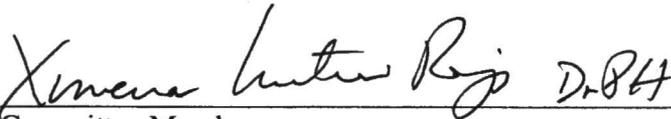
EDUCATION OF PARENTS OF NEWBORNS WITH
CLEFT LIP/CLEFT PALATE BY HEALTHCARE
PROFESSIONALS IN TEXAS HOSPITALS

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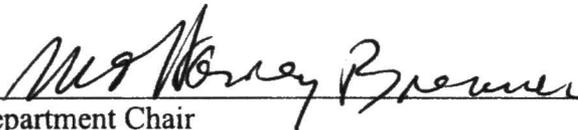
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PROFESSIONALS IN TEXAS HOSPITALS

THESIS

Presented to the School of Public Health

University of North Texas
Health Science Center at Fort Worth

for the Degree of

Master of Public Health

By

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Fort Worth, Texas

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TABLE OF CONTENTS

	Page
INTRODUCTION.....	1
METHODS.....	7
FINDINGS.....	10
DISCUSSION.....	16
CONCLUSION.....	23
APPENDICES.....	26
REFERENCES.....	36

INTRODUCTION

Cleft lip and/or palate is one of the most common birth defects, affecting 1 in 700 births. It is the most common facial abnormality. In 1999-2000, the most current statistics available, there were 436 babies born in Texas with cleft palate alone (without cleft lip) and 760 babies born in Texas with cleft lip with or without cleft palate, according to the Texas birth defects registry (1999-2000 from <http://www.tdh.state.tx.us/>). Cleft palates occur in more males than females. Cleft palate repair is usually done in stages. Primary repair is generally done at approximately 10 weeks, palatal repair at approximately 9-12 months; if needed, secondary repair, alveolar cleft repair, and final repair are done at 4-6 years, 8-10 years and at 14-16 years respectively (Texas Pediatric Surgical Associates n.d.).

The purpose of this study was to ascertain what, how and when, to whom and by whom information about cleft lip and/or palate is disseminated to parents in Texas hospitals immediately after the birth of a child with this congenital malformation and what additional information hospital staff would like to have available for these parents. The examination of the information and support given to parents of newborns with cleft lip and/or palate by health care professionals in the hospital about their infant's birth defect is important because this information has the potential to impact decisions which have lifelong implications on the physical and emotional health of the child and the parents.

This study might also be a catalyst for a review of how and when health information is disseminated to patients in general by health care providers and in-patient health care educators.

Preliminary informal exploration conducted to gather information, about education and advice, on issues such as breastfeeding or resources, provided to parents of babies born with cleft lip and/or cleft palate included informal discussions with: a pediatric nurse, hospital discharge social workers, hospital patient educators, a plastic surgeon, a pediatrician and others. These discussions revealed a general lack of formal guidelines for appropriate, inclusive and in-depth information given to parents by health care professionals immediately after the birth of a baby with cleft lip and/or palate about the condition in general as well as specific concerns, such as feeding the baby and surgical repair for the deformity.

Furthermore, when trying to discern what, how and by whom information was given to these parents, many of the professionals consulted seemed unsure of what kind of information or educational material was provided, if any, and when and from whom the parent received it; i.e.: was it the pediatrician, the surgeon, the health educator, lactation consultants, or the neo-natal nursing staff? Was it given at birth, at the 2 week check-up or at the surgeon's office, or another time/place?

The information garnered and analyzed by this thesis is relevant to public health because, as stated, cleft lip and cleft palate comprise one of the most common birth defect in the United States. It is very important that parents, especially new mothers, of a cleft lip and/or cleft palate baby receive immediate and accurate information about this

condition. This is especially the case if the cleft had not been diagnosed (with the use of ultrasound) prior to delivery because the shock and grief experienced by the parents often make it difficult to absorb information and because their access to information is more limited.

Providing timely information and educational materials for parents is essential. Particularly important concerns are: 1) ensuring that proper bonding occurs between the infant and the mother, and 2) ensuring that the baby receives the appropriate nutrition either through breastfeeding, when possible, or special feeders made especially for babies with cleft palate.

Literature Review

The importance of bonding between a mother and her baby immediately after the baby is born is documented in the literature. (La Leche League International, 1996; Wight, 2000, Children's Hospitals and Clinics, 2004), However, when the baby is born with a deformation, this bonding process can negatively affect the mother/child relationship. (Klaus and Kennell 1982). Also, observations of these patients, i.e., parents who have had babies with a congenital malformation, suggest that early crisis counseling in the first months of life may be particularly crucial in parental attachment and adjustment (Drotar, 1975). Therefore it is important that parents get immediate information about special care for the baby, as well as additional information on sources of support.

While bonding is important in the health and well-being of the new born, proper nutrition is a matter of life-and-death. Literature and studies have shown that breast milk provides many benefits to mothers and babies (Department of Health and Human

Services, Maternal and Child Health Bureau, 2003; Lawrence, 1997) as well as lifelong protection against diseases (American Academy of Pediatrics, 1997), including a decrease in otitis media in infants with cleft palate (Paradise and Elester, 1994). Young, O’Riordan, Goldstein and Robin (2001) found that parents of newborns with cleft lip and/or palate “... frequently leave the hospital with many unanswered questions because health care professionals do not educate them adequately.” These parents identify feeding as having very high priority for information that is critical to them.

Preliminary informal interviews with a plastic surgeon, a mother of a baby born with a cleft conducted by the investigator for this study, suggested that sometimes these mothers are not given the full range of information that they need to make decisions about breastfeeding their infant. Often the extent and type of cleft palate will determine how the baby must be fed. Research has suggested that some mothers intend to breastfeed, but then once the child is born with this difficulty they may not get the adequate training they need to actually do so. In a study of 100 parents of children born with cleft lip and/or palate in South East Wales, Oliver and Jones (1997) found that prior to birth, the majority of mothers intended to breastfeed their child; however after birth, the majority of infants were bottle fed. According to the study, the major criticism of the service offered, to parents and their children, was the poor quality of advice on feeding their children, both in hospital and on discharge (526). Additionally, many mothers do not know that they usually can breastfeed a baby with cleft, even immediately after repair surgery (Weatherley-White, et al, 1987, pp. 879-885) and that doing so will reduce the sedatives required (Herzog-Isler and Honigman, 1996).

Research has shown that physician support is imperative in encouraging breastfeeding especially in a situation that might be considered more challenging and if use of formula or bottle might be the norm. According to Castro, A. and Marchand-Lucas, (2000, p. 234,) “even though physicians acknowledge the superiority of breastfeeding over artificial feeding...physicians tend to prescribe formula at the first sign of a possible problem.”

The U.S. Department of Health and Human Service’s 2000 (p.15) “Blueprint for Action on Breastfeeding” states that hospital practices influence breastfeeding initiating and that such things as the “baby being put to breast immediately in delivery room...[a] woman helped by staff to suckle baby in recovery room and encourage[ing] and reinforce[ing] breastfeeding immediately on labor and delivery” strongly encourages breastfeeding. Hospital practices which separate mother and infant at birth or a “woman given infant formula kit and infant food literature” or “previous failure with breastfeeding experience in [a] hospital” strongly discourages breastfeeding initiation.

Breastfeeding promotes stimulation of the muscles in the face and around the mouth used for speech and contributes to normal development of speech and language as the baby grows, which is of particular interest for the baby with cleft lip and/or palate (Broad and Duganzich,1983). In babies with cleft lip and/or palate breastfeeding has shown to provide protection against upper respiratory infections, particularly otitis media. In addition, successful breastfeeding helps normalize the infant to the family (Danner, 1992 [abstract]).

Study's Goals and Objectives

The purpose of this study was to ascertain what, how and when, to whom and by whom information about cleft lip and/or palate is disseminated to parents in Texas hospitals immediately after the birth of a child with this abnormality and what further information hospital staff would like to have available for these parents in 159 Texas hospitals which had more than 500 births in 2003/2004. The objectives of this explorative study were to ascertain:

- a) who provides information parent immediately after the birth of the child, that is, prior to their leaving the hospital;
- b) what information is given;
- c) how the information is provided;
- d) when and to whom such information is provided to parents and
- e) what further information respondents would like to make available to these parents.

These objectives were accomplished by talking with the hospital neo-natal unit health providers and staff.

METHODS

This exploratory study was conducted using a short open-ended telephone interview with a purposeful sample of health care providers of all of the 159 Texas hospitals which had more than 500 births in 2003/2004, according to the American Hospital Association. The neo-natal unit of each hospital/medical center was contacted by telephone. The researcher asked to speak to the staff member responsible for providing educational materials to the parent of the child born with this birth defect. If the interviewer was told that the parent was given information by the pediatrician or the surgeon or the lactation consultant, then an attempt was made to determine what information is given by that person. In some cases it was necessary to speak to more than one person at a hospital as parents may receive information from various sources.

As stated above, the information was gathered through telephone interviews using a short questionnaire which was developed by the investigator specifically for this project. The questionnaire was designed to answer the general questions of who, what, when and how information is given to these parents, how effective the respondents believe the information to be, and what other information the respondents would like to have available about cleft lip/palate for these parents. (See appendix).

A short, open-ended interview format was chosen because open-ended interviews elicit original responses that can be compared for common themes among healthcare professionals in similar positions, and “the exact instrument used in the evaluation is

available for inspection by those who [might] use the findings of this study” (Patton, 2002, p. 346). Due to the nature of the interview (being conducted while respondents were working) it was important that “the interview is highly focused so that respondents time is used efficiently” (Patton, 2002, p. 346). This also helps to ensure that “[data] analysis is facilitated by making responses easy to find and compare” (Patton, 2002, p. 346). Finally, because using open-ended questions can spark investigation for further research.

The proposal for this exploratory study was submitted for review to the Institutional Review Board (IRB) office at University of North Texas Health Science Center and was found to be exempt from review.

The 159 Texas hospitals which had more than 500 births in 2003/2004, (according to the American Hospital Association) were contacted for interviews of relevant nursery personnel. Of these hospitals, two no longer had maternity units and one hospital was closed. The remaining facilities, 156, were included in the sampling frame. At least 1 attempt was made to contact all of the hospitals. Attempt was defined as the actual contact made with someone in the nursery even if the researcher was unable to conduct interview at that time. Reasons documented included: relevant person not in or busy; researcher told to call back at another time, or leave a message for a particular person; called 2- 3 times and usually leaving messages requesting a return call whenever possible. Contact and interviews were conducted with hospital personnel at 97 of the hospitals. Two of those hospitals immediately transfer all babies born with cleft lip/palate to other hospitals for the purpose of more services for the infant. One of those hospitals

transfers only the baby, so the feeding and bonding issues surrounding this situation seem worth investigating.

A total of 97 respondents were interviewed. Forty nine of the respondents were nursery nurses, 7 were nursery charge nurses, and 13 were nursery clinical supervisors, managers or coordinators. Twelve of the respondents were nurses in the NICU (neo-natal intensive care unit), 10 were Clinical Nurse Specialists and/or directors of specialty clinics (including cleft lip/cleft palate clinics). Seven of those interviewed were nursery Educators, 3 were Pediatric Occupational Therapists (OTs) and 2 were Nurse Practitioners.

FINDINGS

In reviewing the responses to each of the five questions, general patterns are discernable and have been grouped to show meaningful data. Because of the open-ended nature of the interviews, some questions elicited multiple answers. For example, if the respondents gave the response of “nurse and Pediatrician” to question number 1 (see appendix), each response was recorded and has been counted accordingly. In most cases the responses are listed from most commonly to least commonly given and in some cases the responses were arranged chronologically (as in responses to question number 3). In addition to basic counts of responses actual quotes from the respondents are included in the appendix. Each different quote represents a response from a different respondent. The quotes are grouped below into categories based on similar responses, to elucidate the rationale of how and what information is given, and allow further inferences.

1. Who (title or titles) gives information to moms in your hospital when they give birth to a baby with cleft lip and/or cleft palate?

Who gives information to moms?	Number giving this reply
Nurses (including nurse practitioners and NICU nurses)	86
Pediatrician	47
Attending physician/doctor (unspecified)	19
PT (Physical Therapist)/OT (Occupational Therapist):	15 (“especially if feeding issues”)
Neonatologist	12
Social Workers	10
Lactation Consultant/WIC staff	9
Speech Therapist	9
Cleft Palate “team	8
Surgeons (Plastic):	7
OB (especially if condition is known prior to delivery):	6
ENT doctor	2

2. What information is given?

Information given to parents	Number giving this reply:
Feeding	62
Breastfeeding/nursing	26
Haberman feeder	23
Other types of feeders/pumps	13
General information about the condition (including: causes, treatment options, anatomy & physiology, emotional issues, care-at-home, complications- i.e. dental/hearing)	61
Surgical repair/referral to surgeon	25
Additional resources (such as; support groups, ECI, internet resources/web-sites, CPR, organizations-such as Cleft Palate Foundation)	13
Reassurance	4

3. B When is the information given?

When:	Number giving this reply:
Admission of mother (if known prior to delivery):	6
As soon as possible after birth (labor/delivery, as soon as mom aware)	57
First feeding	14
Continuously	9
Within 48-72 hours	9
When Pediatrician makes rounds	3
Slowly (“give parents time to grieve”):	4
When parents ready for information	3

Twenty eight respondents specifically mentioned the “shock” and “grief” and feelings of being “overwhelmed” by the parents as impacting their dispensing of information. In general it was assumed that it was better to educate these parents more slowly, and as they ask specific questions, rather than inundating them with information which they might not be prepared to absorb.

3. B. Are both parents and/or any other family members generally present?

Who is given the information:	Number giving this reply:
Mom only	8
Mom and dad/significant other	30
Mom and all primary caregivers	19
Mom and as many others as possible (family/support members)	11
Mom and grandparents	8
Mom and whoever else happens to be in the room	4

Two respondents stated that Hispanic fathers will not be involved or seem to have more difficulty with a child born with a disability. And 3 respondents cited HIPAA (Health Insurance Portability and Accountability Act) as being a consideration on who/how information is given to families.

4.A. How is the information given (i.e. brochures, discussion, video, etc.)?

How is information given?	Number giving this reply
Verbally (discussion and demonstration-esp.of feeding)	69
Verbal only	13
handouts, brochures, booklets, and/or packets	67
Video	15
Nurses pull information from the internet	11
Micromedex (a health/medical specialty database)	2
internet available for patients to pull information for themselves	1
Refer to web-sites	2
Refer to specific support group	1

4. B. Is information given in the same language that the parent speaks?

Thirty of those interviewed said that they give written information in Spanish as well as English (sometimes translating information from the internet) and 21 specified that they have written information in English only. Twenty one respondents said that they use a staff member to translate information to patient in another language, if necessary, 8 use the At & T language line and 1 said that they use family members.

5. A. Based on your experience: how effective is this information?

Effectiveness of information	Number giving this reply
Very effective	39
Effective/pretty good	35
Not sure	14
Not effective	1

Seventeen of the respondents who stated that the information they gave to parents was “very effective” or “excellent” had before/after photos that they shared with parents of babies from their hospitals and/or actually had nurses or doctors or other parents who had babies with cleft l/p come in and talk with the parents and show photos of their babies. (See appendices for actual quotes from respondents)

More than ¾ of respondents categorized the effectiveness of the information that is given to parents as very effective, effective or very good. Of those who elaborated on their response 20 said that they knew it was effective because they gave immediate referrals (for surgeons, repair, etc.), 7 of those interviewed who said that they felt the information given was effective because parents brought babies back post-op to show surgical results, 5 said that it was because the babies left feeding well and 2 said that they knew the information was effective because babies were not readmitted for failure to thrive.

Fifteen of those interviewed categorized the effectiveness of the information that is given to parents as ineffective or said that they were unsure of its effectiveness. Of those respondents who elaborated on this response, the following reasons were cited: there were so few cases seen at that hospital that they could not judge the impact of

information given or the patients were there for such a short time and no follow-up was done at the hospital or the parents were in such grief the impact of the information given was difficult to assess.

Interestingly, neither the size of the hospital nor its location in a large metropolitan area seemed to be the crucial factor in the respondent's perception of the level of effective information they provide. In fact, easy referral to nearby specialty clinics seemed to, in some cases, delay the parents from getting immediate information, as nurses defer to the specialty clinics.

5.B. What additional information do you think the mom and parents should receive?

Additional information wanted	Number giving this reply
All inclusive booklet/pamphlet with up-to-date information on resources, general info. about condition, timeline (for surgical repair, or other treatment)	12
Support groups (emotional):	12
Knowledge of condition prior to delivery (or at least "discussed in pre-natal classes"):	10
Information in other languages (esp. Spanish and Vietnamese):	7
"Success stories" from other parents/ before and after pictures:	7
Complete kit with feeders/nipples, etc. (free if possible):	5
Lactation consultants:	2
Better referral information (lists of doctors with maps to offices):	2
Surgeon to visit in hospital	1
Local surgeon:	1
Six month follow-up visit	1

DISCUSSION

The responses to the first interview question of who gives the information, indicates that most of the information is given by the physician and the nurses in attendance, with at least some information almost always given by the nurses. Other studies have shown that the parents are initially informed of the situation at the child's birth (90%) and were informed by a physician (96%) (Strauss, et al, 1995). However, the results from this exploratory study indicate that, while it might be the physicians who first tell the parents about the condition, and perhaps where they might go for surgical repair, almost without exception, it is the nurses who work with the mom on feeding the baby and provide (if indeed it is provided) the ongoing education to her about cleft and outside resources and support.

In response to the second question regarding what information is given to the parents, the primary concern of the majority of the respondents and of the hospital, as stated is the feeding of the infants. In fact, that seems to be the primary measuring tool of the effectiveness of the information given to parents, as the baby does not leave the hospital until it is feeding well enough to receive appropriate nutrition.

Almost half of the respondents who listed feeding as information given, talked about breastfeeding and more than half mentioned either Haberman (special nipple for bottles used with cleft babies) or other special feeders.

The responses from the interviewees regarding the way that babies with cleft can be fed can be generally broken down in one of the following three ways (See appendices

for actual quotes). Those respondents who espoused that breastfeeding is very difficult if not impossible when a baby has a cleft. These interviewees said that breastfeeding is either not addressed at all as an option or the mother is told/taught immediately to use a special feeder. Whether or not these mothers are taught to express (pump) their own milk to use in these bottles is unclear. Those respondents who said that they advocate breastfeeding as the very best option, especially with cleft babies and should be strongly and uniformly encouraged. And, finally, respondents who indicated that feeding was the number one goal of the hospital whether it was done with a special bottle (usually the first choice) or by breastfeeding (generally encouraged only at the request of the mother)

Informants gave conflicting responses on how well babies with cleft (especially cleft palate) can breastfeed. Some reported that breastfeeding actually seems to work best for feeding babies with cleft palate while others stated that it was virtually impossible for babies with cleft palate to be breastfed.

Interestingly, the more negative responses (as evidenced in their quotes) to breastfeeding babies with cleft palates seemed to be when lactation consultants were interviewed or when respondents stated that they were utilized. It is unclear if this is because lactation consultants are called in only when there is an especially difficult situation or if there is a general sense even in that “community” that Haberman (or other specialty feeders) work best when feeding cleft babies. It is also interesting that at least one respondent stated that the “doctor has always just recommended bottle feeding”. The facilities that encourage breastfeeding in general, even if the baby is unable to be

breastfed, often stated that they encouraged the mom to pump her own milk- so that it could be used to feed the baby.

The “philosophy” of the doctor, the facility and/or the hospital staff (including specialists, like lactation consultants) toward breastfeeding (and cleft babies in particular), seems to be a significant factor in influencing the method that will be presented to the mother, perhaps as much as or more than the mother’s own decision (which could be impacted by her sense of shock and grief when the baby is born).

“Unfortunately, the attitude that infants with cleft defects cannot be breastfed often has been the first and most consistent response that the parents and families receive from their health care providers. Health care professionals must provide interventions to facilitate breastfeeding and thus normalize and empower these infants. The first days of life are extremely important for imprinting and learning what position works best.” (Danner, 1992 [abstract].)

This is very important, because, as Oliver and Jones have shown in their study of mothers who have babies with cleft (1997), despite the majority of them planning on breastfeeding their babies prior to delivery, the majority of them do not end up doing so after delivery and many of these parents cite the poor quality of advice on feeding their children “both in the hospital and on discharge” as the reason.

Most of the respondents (67) stated that general information about cleft is also given to the parents. This information seems to include anatomy and physiology as well as cause and information about repairs. Many of the respondents stated that surgical resolution of the cleft seems to be the primary concern of the parents and so, immediate

referrals to surgeons, cleft or cranio-facial clinics, and/or cleft “teams” are an important factor in how the informants measured the effectiveness of information given to patients. Often this information comes directly (or is at least generated by) the physician.

Reassurance was often cited as an important aspect of providing information to parents about their baby’s condition (see appendices for direct quotes from participants). But only about 1/3 of respondents listed outside support services or referral to various relevant resources as the information given to parents and only 1 specifically mentioned a support group. This is significant because as Strauss et al, show in their research (1995), this is a high priority for parents of babies born with cleft. One of the informants in the Strauss survey stated that, “The most important area that the parents of a child born with a cleft lip and palate needs is to have someone to talk to that has been in the same situation. These respondents also stated that the doctors and nurses were no help to us at all.” (86)

Responses to the question when and to whom the information is given showed that information about the baby’s condition (i.e. the fact that the baby has a cleft and that it is repairable) is generally given as soon as possible, either immediately in labor and deliver or as soon as mom is awake/alert enough to take in the information. A few respondents mentioned that this condition is sometimes known ahead of time and so the parent comes in with knowledge of their unborn baby’s cleft . However, using the standard prenatal ultrasonography “the US detection rates of facial clefting have been reported to be as low as 21%-30%.” (Johnson, Pretorius, Budorick, Jones, Lou and James, 2000).

Three of those interviewed said that they wait until the Pediatrician comes in to talk with mom. Most respondents said that information is given at the first feeding. More than 1/3 of respondents described the shock and grief of the parents and the importance of giving parents time to adjust to information, as well as to provide it slowly and continuously as needed. Several mentioned that they just provide information as it is asked for by the mom/parents.

Regarding to whom the information is given, the majority responded that information (especially about feeding) is given to both parents and/or all primary caretakers, very often including grandparents. Only 8 stated that it is usually just the mom who receives the information/education and 3 actually said that HIPAA has impacted who receives the information about the child's conditions.

Responses to question 4, on how the information is given to the mom/parents and language used indicated that the majority (69) of respondents responded that information is given verbally and with demonstration, especially for feeding. The also stated that translation is used as needed, and it is provided by a staff member, usually a nurse or doctor or the AT & T language line. Only 1 mentioned using a family member to translate. Most of the respondents (67) also had some kind of written information to give to the parents (with almost ¼ being in English only). The lack of Spanish brochures was cited by some respondents as being of concern. Research by Edwards and Bonilla (2004) on availability of educational materials in Spanish for parents of babies with cleft, reported that many craniofacial teams expressed a need for more Spanish-language educational materials on specific craniofacial conditions; additionally, many expressed

frustration in communication and interaction with Spanish speakers. ([abstract]) This is especially relevant to this study of information given to new parents of baby's born with cleft because 2 of the respondents specifically mentioned that Hispanic fathers seem to have the most difficulty adjusting to their child's abnormality.

Another issue of concern regarding how the information is provided, relates to verbal versus written information, as more than 1/10 (13) of the respondents said that they provide only verbal information. This is of concern since that 1/3 of those interviewed said that the parents were experiencing so much shock and grief that they had a hard time taking in much information. Parents would benefit from receiving information that they can refer back to and read again as needed for reassurance, resources and understanding.

Language and sources of information issues were also raised; 15 respondents said that they have a video for parents (although no one mentioned a video in Spanish). Several respondents said that they pull information off of the internet. They stated that such information was current and could be printed out in the language needed. One respondent said that patients in their hospital, in an affluent suburb, have access to the internet and can also to choose to peruse the internet themselves for additional information.

Opinions about the effectiveness of the information respondents give out and their ideas on other information/educational materials that they might find useful were also ascertained.. The majority of respondents felt that the information they give to parents is either very effective or effective. Most of the time, as stated above, this was based on the

fact that the babies were feeding well when they left the facility and the family was given an immediate referral for consultation for surgical repair. In some cases the surgeons even come to the hospitals before the child is released.

The 39 respondents who rated the information they give patients as most effective almost always said that an important part of the information they share with parents are “before” and “after” corrective surgery pictures of other baby’s born with cleft lip and/or palate . Several also mentioned that the moms would bring the babies back in the hospital after the surgery just to show the staff/nurses the success of the repair. The existence of a network of local moms or medical staff whose child had the same condition was also mentioned (see appendices for quotes from respondents).

Those respondents less sure of the effectiveness of their information cited either the fact that their hospital has very few cases of baby’s born with cleft , or the fact that these patients are not seen at their hospitals for follow-up and so it is difficult for them to measure the efficacy of the information which they provide.

Additional needs reported were: a complete updated “kit” that would contain literature (in whatever language was appropriate) about; the condition, causes, repair, feeding, list of surgeons and/or teams for referral (and maps to their offices) and/or a video; a kit with the special feeders, especially Haberman; resources for financial assistance; local support groups; and means to provide screening prior to delivery so parents could be aware of the condition.

CONCLUSION

The information gathered from this exploratory study indicates that information given to new parents who have babies born with cleft lip and/or palate in Texas hospitals is inconsistent and sometimes insufficient (as indicated, in part, by the fact that more than 1/3 of respondents said that they'd like more information for parents) throughout the state. Interestingly, neither the size of the hospital nor its location in a large metropolitan area seemed to be the crucial factor in the respondents perception of the level of effective information they provide. In fact, easy referral to nearby specialty clinics seemed to, in some cases, delay the parents from getting immediate information, as nurses defer to the specialty clinics.

Physicians seem to be the ones who convey the initial diagnosis to the parent, and perhaps provide information on the referral to the surgeon, however, it is the nurses who provide the majority of information to the moms, i.e., information about feeding babies with the condition, general information about the condition and emotional support in the hospital, as well as information on resources and support after discharge. Whether most of the hospitals have professional staff who are fully trained on the educational techniques of breastfeeding babies with cleft conditions is less clear. Therefore further exploration of this area would be of value.

Many of the respondents agree that parents could benefit by additional information available to them. While there are a plethora of resources for parents and medical personnel available on the internet, this information needs to be made available

to parents along with consoling information, e.g., before and after pictures, when they go home. Resources on where to receive emotional support, especially from other parents-support groups in the community or online are also needed. As mentioned above, a comprehensive kit with this information as well as information on special feeding equipment, could be made-up for parents, or downloaded from one of the many web-sites that do have this information available. All of the hospitals with neo-natal units should have a video on hand for parents to watch while they are in the hospital. All of these materials need to be available in Spanish also.

It is imperative that the hospital staff (especially the nurses and Pediatricians) of neo-natal units be educated (either in nursing school or as part of their required continuing education) about the importance of providing immediate, comprehensive and relevant information to parents of newborns with cleft lip and palate. It is important that these providers understand the huge impact the information (or lack of information) they provide can have on the emotional and physical well-being of cleft lip/palate babies and their parents, including and especially bonding and feeding issues (i.e. breastfeeding options, community support resources, appropriate web-sites, etc.). Texas hospitals need to adopt a program to ensure that no matter where a baby with cleft lip/palate is born in this state, each new parent will be given the same information and access to the best care for their baby and for themselves to help provide a level playing field for all Texas infants.

The primary limitation of this project is that the investigation of what, how, who, and when information is given to patients who give birth to babies with cleft lip and/or

palate is based solely on participants responses to the interview, without being supported by additional qualitative or quantitative research such as observation and/or individual parental interviews. Although surveys of parents of newborns with cleft lip/palate have been taken in other studies, it would be valuable to conduct a study with a sample of parents who had delivered babies in the hospitals surveyed in this exploratory study to find out how their experiences with the information received paralleled with the impressions of those providing the information. Also, information provided by pediatricians and/or surgeons and Cleft Lip/Palate teams was neither sought nor ascertained in this study, and would probably provide additional relevant information.

APPENDIX A
QUOTES FROM RESPONDENTS

Quotes from respondents

The following quotes from respondents are included because they elucidate points made in the paper about the general nature of responses to a particular interview question (2 or 5) or a subject that the informant introduced as part of an answer, such as feeding as a response to “what information is given” in the second question. All quotes are included from each respondent who elaborated on a given topic beyond a single word or two.

Question 2. What information is given?

feeding

The responses from the interviewees regarding the way that babies with cleft can be fed can be generally broken down in one of the following three ways, as illustrated by the quotes following each category.

1) Those respondents who espoused that breastfeeding is very difficult if not impossible when a baby has a cleft

“lactation consultant will work with mom- but has never worked with Cleft l/p babies-so just demonstrate special nipples”

“doctor has always just recommended bottle feeding”

“This hospital has high breastfeeding rate- lactation consultant attempts but when palate involved difficult, usually go to Haberman feeders”

“lactation consultant at hospitals- but usually nurses teach Haberman feeder at first feedings”

“do not do training in breastfeeding for cleft lip/palate babies- after baby is fit with prosthesis at specialty clinic might be taught to breastfeed at that time [we use] specialty bottles for feeding.”

“nurses have special feeders- if trouble feeding [then] transferred [to another facility]”

“have lactation consultant, but [we] have never had a baby with a cleft be able to nurse because you have to have the perfect condition to get a seal”

“[teach] feeding with special bottle and positioning and have pictures for feeding”

“teach them to use Haberman feeders, have 2 lactation consultants if necessary”

“lactation consultants[utilize]- teach Haberman feeder”

“train with Haberman feeder”

“nurses use special feeders”

“[instruct] on feeders and bottles”

“[if] feeding issues, have nurse or doctor teach Haberman feeders, no lactation consultant”

“utilize feeding specialist – OT- discusses formula/nipples, etc.”

“If cleft lip only- then try to breastfeed”

“feeding specialist [determines] feeding outcomes”

2) Those respondents who said that they advocate breastfeeding as the very best option , especially with cleft babies and that it should be strongly and uniformly encouraged.

“try to encourage breast feeding- seems to be best with cleft palate because breast covers hole and allows sucking-but nurses extensively trained with cleft palate special nipples, etc.”

“encourage breastfeeding [this] works best- molds to cleft – try to get mom breastfeeding right away- but have Haberman feeders on hand”

“usually [baby] nurses okay, seals okay, then don’t have a problem, [there is] no lactation consultant, but have Haberman feeder and special lamb/double nipples, sometimes supplemental feeding necessary”

“Try to [encourage] breastfeeding if possible – seals off palate when breastfeeding – but all of the nurses have been trained to use Haberman feeders”

“use Haberman feeder if necessary”

“breastfeeding works best – if can’t nurse with cleft l/p then evaluate feeding...”

“try to let breastfeed if [mom] wants to – so accommodate parent”

“breastfeeding consultants- ladies from WIC- called in if breastfeeding”

“ ‘breast is best’-even cleft l/p – seals over cleft...”

“encourage breastfeeding- used to teach to feed on side without the cleft, now learned to teach to nurse on the side with the cleft”

“[call in] OT or lactation consultant if necessary to help with breastfeeding – [should have] more information and education about breastfeeding controversy [with cleft l/p babies] and on bonding with baby”

3) Those respondents who indicated that feeding was the number one goal of the hospital whether it was done with a special bottle (usually the first choice) or by breastfeeding (generally encouraged only at the request of the mother)

“lactation consultant- if necessary- to breastfeed”

“breast feeding if possible, no lactation consultant, nurse helps with bottle [if necessary]”

“breastfeeding if possible, [have] Haberman feeders”

“nurse [gives information] on breastfeeding or other feeding options”

“[the mom’s are] really encouraged to breastfeed [but it’s] not very successful, because no follow-up, have had several [moms with cleft l/p babies] who have gone to Latin America and Guatemala and do fine [because] breastfeeding is much more successful in Latin countries”

“[we] encourage nursing and have special bottles and nipples for feeding”

“nurse teaches breastfeeding – but have [special] bottles and information on where to get them”

“teach to feed with special bottle or breastfeed”

“training on feeding with special bottles- Haberman feeder- usually start with breastfeeding...”

“lactation consultant can be called in if mom wants to [nurse] depends on baby too”

Reassurance

“reassuring – not your fault/not genetic”

“It’s fixable/surgical outcomes”

“ensure bonding process happens/ initial evaluation involves calming parents a lot of education and nurturing”

5. Based on your experience: how effective is this information?

The 39 respondents who rated the information they give patients as most effective almost always said that an important part of the information they share with parents are “before” and “after” corrective surgery pictures of other baby’s born with cleft lip and/or palate . Several also mentioned that the moms would bring the babies back in the hospital after the surgery just to show the staff/nurses the success of the repair. The existence of a network of local moms or medical staff whose child had the same condition was also mentioned.

“[we] ensure bonding process happens before [mom and baby] leave the hospitals-have testimonials from other parents [who have had babies w/ same condition] share positive results]

“have a scrapbook we share made by a family of baby born here [with cleft l/p]...”

“[have] a network of moms [who’ve had babies w/ cleft l/p]- exchange information- and call the [new] mom when she gets out of the hospital”

“[we have] families in town who’ve been through this who we call to come up and visit [with the new mom] and share experiences and knowledge and bring a child who has had cleft repaired”

“(the) best thing is to be positive- [we share] a list of movie stars, etc. who’ve had successful [cleft lip/palate] repairs- [we tell the parents] if your child is going to have a birth defect this is the best one to have because [it’s very repairable] and the child can go on to have a normal life”

“[We] recently had a big success story – one young mom had a baby with cleft l/p- she had had no pre-natal care and so it was a complete shock, the mom wouldn’t even hold the baby and a mother who had had a baby [with this condition] brought in before and after pictures of the baby and the [new] mom eventually accepted her baby.”

APPENDIX B
QUESTIONNAIRE AND *COVER LETTER*

“Cover Letter” for Telephone Questionnaire
(Investigator will read this to respondents prior to beginning the interview)

It is critically important that a new mother of a baby born with cleft lip and/or cleft palate receive immediate information about this condition.

Providing timely information and educational materials for parents is essential to ensure:

- 1) that proper bonding occurs between the infant and the mother,
- 2) that the baby receives the appropriate nutrition from the mother, via breastfeeding or expressed breast milk or an alternative of her (educated) choosing.

For this reason, an exploratory study is being conducted as a thesis project at the University of North Texas Health Science Center, to determine and compare the protocol hospitals use to disseminate information about cleft lip and/or palate to parents (especially the new mother) in the hospital immediately after the birth of a child with this condition.

This telephone interview is for information purposes only. Participation in this research is completely voluntary and there was no way to identify you as a participant since we are not asking for any identifying information. Your choice to participate (or not participate) in this survey will not affect your employment in any way.

If you have any questions about this interview, please feel free to contact the major advisor to this study, Dr. Sue Lurie at the UNT Health Science Center 817-735-2451.

Thank you for your participation.

Telephone Questionnaire

Date: _____ Hospital: _____

Number of live births at this hospital in 2003/2004, according to the American Hospital Association (AHA). _____

Title of person being interviewed: _____

1. Who (title or titles) gives information to moms in your hospital when they give birth to a baby with cleft lip and/or cleft palate?

2. What information is given?

3. When is the information given? Are both parents and/or any other family members generally present?

4. How is the information given (i.e. brochures, discussion, video, etc.)? Is it given in the same language that the parent speaks?

5. Based on your experience: how effective is this information? what additional information do you think the mom and parents should receive?

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