CARE GIVERS' PERCEPTIONS OF THE ROLE OF THE HOME CARE THERAPIST IN NON-ORAL FEEDING INTERVENTION IN FAILURE TO THRIVE PATIENTS

A THESIS

SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENT

FOR A DEGREE OF MASTERS OF ARTS

IN THE GRADUATE SCHOOL OF THE

TEXAS WOMAN'S UNIVERSITY

SCHOOL OF OCCUPATIONAL THERAPY

BY

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AUGUST, 1995

TEXAS WOMAN'S UNIVERSITY
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To the Associate Vice President of Research and Dean of the Graduate School:

I am submitting herewith a thesis written by Audrey Bell entitled "Care Givers' Perceptions of the Role of the Home Care Therapist in Non-Oral Feeding Intervention in Failure to Thrive Patients." I have examined this thesis for form and content and recommend that it be accepted in partial fulfillment of the requirement for the degeee of Masters of Arts with a major in Occupational Therapy.

Mary J. Baxter MA, OTR
Mary F. Baxter, OTR, MA
Major Professor

I have read this thesis
and recommend its acceptance:

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Accepted Leslie M Thompson
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August, 1995

As the nation tries to curtail spending in the health care industry, more physicians are using home health care to provide intervention for their patients. Infants who are deprived of oral feeding for prolonged periods experience great difficulty establishing oral feeding while they are recovering from medical problems. The purpose of this naturalistic inquiry study is to investigate care givers' perceptions of the home care therapist role in feeding intervention. Interviews using open-ended questions were completed with five care givers of Failure to Thrive children. Data was transcribed in narrative form. Results indicate that care givers valued the intervention that they received from home care therapist and they would recommended home care to other families when appropriate.

CHAPTER I

INTRODUCTION

Home care has become a growing area for occupational therapy. The provisions for occupational therapy in the home are challenging, rewarding and exciting. The occupational therapists offers a very practical and functional service in teaching patients to achieve a maximum level of independence in their familiar surroundings. Occupational therapists make a unique contribution to home health care by applying their skills in observation, assessment and environmental adaptations.

Family coordination, involvement and training are basic components of all home-based treatment. The primary care givers should have input in the therapeutic approach and goal setting. The family should be taught how to assist in attaining goals, and the family members need to be involved in setting up routines and schedules.

Statement of the Problem

A number of factors point to the increasing use of home care for pediatric patients. During the last decade, equipment has developed that is easily transportable in to the home. The spiraling cost of hospital care was another factor pointing to the need for home care as a treatment option. As the nation tries to curtail health care spending, many patients are forced to chose home care before they are fully recovered (Anderson, 1994).

In today's health care environment, there is no question, but that an alternative to expensive and lengthy hospital stay is necessary. Home health care can provide the key to healing in a more cost effective and expedient manner (Anderson, 1994). In addition, pediatric patient benefits from being at home in close contact with loved ones.

Over the past thirty years, occupational therapists have placed increasing value in the role that care givers play in children's development and consequently have promoted care givers participation as an integral part of the early intervention process (Moersch et al. 1989). An extension of this belief and practice indicate that home programs have become an accepted way to enhance care givers participation in working on therapy goals at home so that the child's skills can be generalized to a natural setting.

Statement of the Purpose

The purpose of this study is to investigate care givers' perceptions of the home care therapists role in feeding intervention of Failure to Thrive patients. This study is a naturalistic inquiry that will address the following questions:

1. What are the care givers' perceptions of how the home care therapists assists in feeding intervention with their children?
2. How are care givers taught the interventions suggested by the home care therapists? What is the preferred method of learning the intervention?
3. What techniques do care givers use most often when feeding their

children?

4. How do the suggestions made by the home care therapists affect the family schedule?

5. Do care givers see improvement in their children's feeding intervention?

6. How do they tell other families about the value of home care?

Background and Significance

There is little written about tube to oral feeding. Although literature on the feeding process as related to the developmentally disabled population is readily available, literature on the process of initiating or reinstituting oral feeding following prolonged period of tube feeding is limited (Dunbar et al. 1991). Various gastrointestinal disorders and medical conditions necessitate the use of total parenteral nutrition (TPN), nasogastric or gastrostomy tubes as a means of providing adequate caloric intake and nutrients. During infancy and early childhood, non-oral methods were often used when medical conditions did not permit feeding by mouth. Illingworth and Lister (1964) and Handen, Mandel and Russo (1986) suggested that there are critical periods in infancy in which normal nutritive feeding patterns develop. Tongue mobility improved when pureed food was presented at the age of four to six months of age, thereby preparing a child for future chewing (Blackman et al. 1987).

Occupational therapists providing intervention in pediatrics are faced with many children who have feeding problems and must be fed by

gavage feeding. Providing an infant with a pacifier during gavage feeding has been shown to improve weight gain by improving digestion (Anderson, 1994). Other techniques for improving feeding included tactile stimulation to the oral musculature prior to feeding, along with jaw stability and maintenance of a midline head position with chin tuck and semi-flexed positioning.

Common characteristics of children who have difficulty making the transition to oral feeding are hypersensitivity in and around the mouth, resistance to food presentation and delayed oral motor skills (Blackman et al. 1987). These are of particular concern to occupational therapists due to the effect on feeding development and general behavior. The significance of the behavioral problem in the form of food refusal and resistance often lead to frustration on the part of both care givers and professionals, resulting in behavioral mismanagement and failed attempts to reinstate oral feeding (Chan, 1981).

Therapists need to involve care givers in collaborative goal setting so they will feel involved with the child's treatment plan. Professionals must also learn to accept the fact that care givers may not wish to work on a goal that the therapists viewed as needed. Professionals must be flexible in accommodating the changing priorities of families as they gain more information and understanding, and as stress diminishes (Katz et al. 1989).

In home care, the care givers, as consumers, should be an integral part and collaborator with the therapists in making decisions about their child's treatment. This belief required the rejection of the medical

model of care in which the therapists was viewed as experts in control. The goal of the collaborative model is to interact with families in ways that support them in controlling their children's health care (Crinic, et al., 1983). Care givers learn intervention and techniques in many ways, therefore the teaching methods used must be carefully considered. Some techniques for teaching care givers include pamphlets, verbal instructions, pictures, written instructions, videos and demonstrations.

Definition of Terms

Certain terms required definition for the purpose of this study.

1. Failure to thrive. (FTT) means that an infant or toddler is not growing, i.e. gaining weight, according to expected growth as established by the National Center for Health Statistics. However, FTT may be difficult to diagnose as no universal criterion for adequate weight gain for a particular child exists.

2. Oral motor feeding skills. Oral motor feeding skills are those skills necessary for the child to ingest nutrients by mouth in order to sustain life.

3. Home setting. This is defined as the place of residence of the child and his or her care givers.

Limitations

Because of the selection criteria, information from this study will be limited to the diagnosis of Failure to Thrive. Due to the limited number of informants, the results of this study can not be generalized

to a larger Failure to Thrive population.

Assumptions

An interview is assumed to be a valid method of data collection.

CHAPTER II

LITERATURE REVIEW

Minimal literature exists regarding the transition from tube feeding to feeding by mouth. From experience, feeding intervention is a long term goal that requires collaboration between the therapists and the care giver. Home Care can provide the key to healing not only faster but more cost effectively (Sanders, 1994). In addition, the pediatric patient benefits from staying at home in close contact with loved ones.

Hypersensitivity around the mouth, resistance to food presentation and delayed oral motor skills are of particular concern to the occupational therapist due to their effect on feeding skill development (Chan, 1981). Vogel (1986) described physical and behavioral causes that may lead to oral defensiveness and the need for tube placement in the pediatric patient. Physical causes included oral hypersensitivity, laryngeal incompetence, nasal regurgitation, pharyngeal incoordination irritation caused by nasogastric tube feeding or a combination of these factors. The main cause was conditioned dysphagia, described as a learned disorder in which the child responded negatively to oral activities due to previous trauma in the mouth and throat. Conditional avoidance to swallow developed as a protective response. The consistent presentation of food in a calm relaxed manner without undo attention being given to negative behavior such as crying, hand pushing or

screaming was a strategy used by the home care therapist. The care giver was encouraged to become fully involved in pre-feeding exercises as well as in the actual food presentation. Handen et al. (1986) used behavioral management which consisted of giving positive reinforcers, such as toys or social play for appropriate eating.

Sensory stimulation and play activities were also successful techniques used in the management of oral feeding problems. Copeland and Kimmel (1989) described occupational therapy intervention using oral stimulation and formula introduction by mouth using various nipple sizes to determine which size was more suitable. The occupational therapist initially began working with a child who was twenty-nine days old. By the age of 2 months, the infant had been weaned from the tube feedings and was taking formula orally in a bottle using a standard size nipple. The feeding program was completed with the care givers education on appropriate oral stimulation prior to feeding as well as behavioral management.

There was also evidence that consumer satisfaction was an important health outcome measure which affected keeping appointment, compliance with treatment and may have been related to improvement in the patients health status (Copeland et al. 1989).

CHAPTER III

METHODOLOGY

Naturalistic inquiry analyzes phenomena as it is observed. Analysis is based on narrative data from transcribed interviews. In the naturalistic inquiry, the researcher and the informant interact during data gathering. Identifying the thinking and action processes of the analytic task increases the likelihood of producing accurate and more credible interpretations and understanding of a phenomena. Data collection is a directed search involving observation of what people do and interpretations about why things are done as they are. Analysis attempts to make sense of what is observed. Naturalistic research enables the researcher to ask questions concerning a phenomena to gain greater understanding from observation of the person's perspective of their world (Schmid, 1980).

Informants

The children of the informants were selected from the home care census list of Texas Children's Hospital. The clients were referred to Rehabilitation Services for occupational therapy. Care givers were screened for their ability to relate their experiences with the home care staff and for their willingness to participate in the study. The children of the informants consisted of five (5) conveniently selected Failure to Thrive patients whose ages ranged from three (3) years to

nine (9) years (Table One). This number of children was chosen so that more indepth information could be obtained from this smaller number. Additionally, potential children were limited to those with the diagnosis Failure to Thrive. The children of the informants had received home care intervention for more than one year. Criteria for the children selected were that (1) the children were medically stable with no surgeries planned, (2) transition to feeding by mouth was a goal of the physician, care givers, and therapist, (3) the children had a recent barium swallow to determine that swallowing was adequate, (4) the physician's order specified a reduction of the tube feeding by twenty-five (25) percent to increase the sense of hunger. and (5) the care givers performed oral motor stimulation followed by offering pureed food by spoon three time a day, seven days a week.

Procedure for Collection of Data

Interviews were chosen to gather data. Interviews offer protection from ambiguous or confusing questions and enhance the quality of self report data through probing. Informants are less likely to answer " I don't know" responses or leave questions unanswered. Face to face interviews have an advantage in their ability to produce additional data through observation of the informant level of understanding, degree of cooperativeness, social class and life style. Demographic information was gathered by the researcher prior to the interview (Appendix A). Then a structured interview format (Appendix B) was used when interviewing the care givers. In each situation

TABLE ONE

INFORMANTS DEMOGRAPHIC INFORMATION

SEX	Child 1	Child 2	Child 3	Child 4	Child 5
Female			X		X
Male	X	X		X	
ETHNICITY	BLACK	WHITE	MIXED	WHITE	BLACK
AGE					
0 - 3 YEARS			X		X
3 - 6 YEARS		X		X	
6 - 9 YEARS	X				
DIAGNOSES	MR/FTT	CLEFT/ FTT	DD/FTT	CP/FTT	FTT
FEEDING TYPE	S	S/NB/G	S	S/G	S/G

KEY TO DIAGNOSES

FAILURE TO THRIVE - FTT
DEVELOPMENTAL DELAY - DD
CEREBRAL PALSY - CP
CLEFT PALATE - Cleft

KEY TO FEEDING TYPE

SPOON - S
NUK BRUSH - NB
GASTROSTOMY TUBE - G

the same questions were asked and in the same order. The interviews were tape recorded and conducted in a one to two hour session in the informant's home. The therapist was in the home but in the next room working with the child. Probing questions were added to get more useful information from the informants than was volunteered during the first reply. The children were identified in a written narrative by a number corresponding to the order of the interview.

Procedure for Reporting Data

The information gathered from the interview was transcribed in narrative form. Similarities and differences in feeding were reported as they related to the research questions.

CHAPTER IV

RESULTS

Five care givers were interviewed using open-ended questions designed to investigate their feeling about home care feeding intervention and to determine their perceptions about home care. The ethnicity of the families chosen were two Black single parent families, two White nuclear families and one mixed nuclear family (Father was Arabic and mother was White). The Black families seemed protective of their children yet they did trust the therapists to feed them.

Child One who was eight (8) years old and who lived in a single parent family. His mother is the primary feeder. Child One was diagnosed Mentally Retarded and Failure to Thrive. Although Child One has a gastrostomy tube, his primary means of feeding was with a spoon. Child One has been a home care patient for one and one-half years. His mother, E.G., learned about home care from another clinic. E.G. felt that having a Failure to Thrive child was difficult when she had to take numerous pieces of feeding equipment for trips away from home. E.G. said, "I remember one horrible experience with a feeding pump that alarmed constantly one night and stopped me from sleeping". E.G. felt comfortable with the intervention that has been taught to her by the home care therapist because she felt that the therapist is very competent. Prior to feeding, the therapist uses lemon glycerin

swabs to stimulate the gums and teeth prior to feeding the child. E.G. offered her child pureed food three times a day, seven days a week. The life style changes that E.G. made include allowing extra time for her child to eat, smelling the food prior to feeding and feeding her child face to face in a calm, relaxed atmosphere. E.G. preferred demonstration to learn the feeding techniques that were taught by the therapist. She participated in the goal planning for her child and she told the therapist that feeding was a priority. E.G. told other families about home care as often as she could. She does believe that home care was a valuable treatment option.

Child Two was White and lived in a nuclear family with his mother & father. He was four years old with a diagnosis of Failure to Thrive and Cleft palate. He is primarily fed by gastrostomy tube but the therapist and his mother, S.F., also feed him with a spoon or a NUK brush. The NUK brush is also used to stimulate the tongue and the palate behind the front teeth prior to feeding. S.F. is the primary feeder. Child Two has been a home care patient for one year and 2 months, yet he has been working with special feeding techniques for one year and one month. Life style changes that S.F. made were feeding her child first, allowing plenty of time between spoonfuls, introducing a new food each week and using meal time for social interaction. S.F. learned about home care through another facility. She initially felt that no one else had a child that was tube fed. S.F. felt that having a tube fed child was very inconvenient because of the need to carry feeding equipment everywhere. S.F. said, "People stared at us when we had to

feed him in public". Child Two is fed every four hours and because he is older, he has difficulty remaining still long enough to be tube fed. S.F. preferred demonstration to learn new techniques and she did participate in goal planning for her child. She would recommend home care to other families. She feels that her child is doing better as a result of home care intervention.

Child Three was three years old and of mixed decent living in a nuclear family with three other family members, (mother, father & sister). Father was also present during the interview but did not offer any information. Child Three had a gastrostomy tube but she pulled it out about 6 months ago. Since that time, Child Three has been eating successfully with a spoon. "The worst part of having a Failure to Thrive child was the inconvenience of carrying all of the feeding equipment when we left the house", said J.A. Child Three requires verbal cues and praise from the person who monitors her feeding. She does not require oral stimulation prior to feeding. Life style changes were minimal but did include allowing extra time for family meals. The physician recommended home care to the family. J.A. depends upon the home therapist and highly recommends home care intervention.

Child Four was four years old and White who lived in a nuclear family with four other family members, (mother, father, brother & sister). Child Four has a diagnosis of Failure to Thrive and Cerebral Palsy. Child Four is primarily gastrostomy tube fed. Feeding by mouth has been a treatment goal for this child, but little success is noted. Mother, E.H., learned about home care from the therapist who worked with

the patient while he was in the hospital. E.H. said, "It is a hassle to gather the feeding equipment when the family leaves the house". Child Four receives a slow milk drip at night. Prior to attempting to feed her child, E.H. uses oral desensitization around the lips and mouth using ice, massage, NUK brush, tongue depressor and strengthening exercises to stimulate chewing and lip closure. Life style changes include allowing extra time for oral stimulation to be followed by the presentation of pureed food and feeding prior to the other family members. Both demonstration and pictures were used to teach the techniques. E.H. participated in goal planning and she continues to do so on an ongoing basis. She values home care because it does not interrupt her day or the family schedule. E.H. was in a parent support group that she tells about the value of home care. She highly recommends home therapy.

Child Five was three years old, Black and lived in a single parent family. Child Five is diagnosed Failure to Thrive. She is gastrostomy tube fed. She uses a spoon to eat approximately one ounce of food three times a day. Child Five has been a home care patient for one year, three months. Mother, S.U., has been working with special feeding techniques since she was referred to home care. Initially S.U. did not feel comfortable feeding her child but after working with the home care therapist her anxiety has diminished. S.U. said that tube feeding requires more preparation and it is very tedious. The therapist taught S.U. special feeding techniques by demonstration. Feeding techniques include gloved hand exercises for the lips and jaw muscles,

lemon glycerin swabs and toothettes used inside the mouth and for desensitization. Child Five does not gag when food is presented on a spoon. Life style changes include feeding face to face while positioned in a feeder seat and feeding in a atmosphere that was free of distractions.S.U. expressed a wish to thank home care for providing a skilled therapist. S.U. said that she has not had the opportunity to tell other families about home care.

All the care givers interviewed felt that demonstration by the therapist with a supervised session for the care givers to demonstrate their understanding was the preferred method of learning. All care givers were provided with the opportunity to participate in goal planning for their children and they felt that home care is a valuable treatment option. Care givers felt that because the treatment is in a familiar place, the children progressed more than if treated in a hospital. All care givers spoke of the inconvenience of carrying numerous pieces of feeding equipment for trips away from home. Although Child Four has progressed at a slower rate in feeding goals than the other children in the study, his care giver has seen improvement with decreased oral defensiveness.

CHAPTER V

DISCUSSION

In reviewing the literature, Copeland (1989) gave credence to the pre-feeding techniques that were used by the home care occupational therapist. Vogel (1986) described a physical cause, oral hypersensitivity, that occupational therapist encounter in feeding dysfunction. Sanders (1994) recognized the importance of home care as a treatment option.

The data presented in the study were based upon data that was gathered from interviews of five care givers of pediatric patients who received home care occupational therapy for feeding intervention. Successful feeding was dependent upon several factors including family scheduling, time restraints, and motivation by care givers. Goal planning with the home care therapists was found to have a significant impact upon the care givers' motivation to implement the transition from tube feeding to feeding by mouth. Interviews revealed that the amount of knowledge that the care givers possessed about the techniques used for feeding led to greater comfort in carrying out the intervention. Because feeding intervention is not a short term goal, consistency on the part of all persons involved in the feeding process was a very important aspect of therapy. Care givers said that having a Failure to Thrive child was very inconvenient and time consuming. Feeding

equipment must be taken when the Failure to Thrive child leaves the home. Care givers expressed positive feelings about the intervention used by the home care therapist and each depended upon the home care occupational therapist for information and resources related to feeding.

Treatment in the home provided an opportunity for the patient to be seen in familiar surroundings and the intervention to be adapted and individualized to the patients' environmental needs. Care givers preferred demonstration from the therapist to learn the intervention. Life style changes that care givers made include allowing extra time for feeding, feeding the child face-to-face in an infant seat or on the care givers lap, allowing the child to smell the food prior to being fed, feeding the child prior to the other family members, using the feeding time as a rich source of social interaction and learning by talking to the child, allowing plenty of time between spoonfuls, introduction of one new food a week, and feeding in a calm relaxed atmosphere free from distractions.

Follow-up studies are indicated to determine the long term effects of the feeding intervention and to determine the average length of time that intervention is needed by the home care occupational therapists. Although this study did not focus on gender or cultural differences, a future study is indicated to gather data on gender and cultural differences. Studies looking at other diagnoses commonly seen in home care would be warranted as well to assess the role and

need for occupational therapy.

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APPENDICES

APPENDIX A

Informant's Demographic Information

APPENDIX A

Informants Demographic Information

1. How many members are in your family?

2. What is your child's diagnosis?

3. What is your child's age?

4. What type of feeding is used with your child?

Formula-filled syringe_____	Tube Feeding_____
Straw_____	Bottle_____
Finger dipped in formula___	Pacifier dipped in formula____
Spoon_____	Other_____

5. Who is the primary feeder of your child?

6. How long has your child been a home care patient?

7. How long has your child been working with special feeding techniques?

8. How did you hear about home care?

9. Do you feel your child has improved as a result of home care?

APPENDIX B

Guided Interview Format

APPENDIX B

Guided Interview Format

1. Tell me what it's like to have a Failure to Thrive child.

2. Tell me about the life style changes you have had to make because of the need to feed your child. (Probing questions may be needed to encourage additional response).

3. How do you feel about the intervention that you received from the home care therapist?

4. Tell me about the techniques used by your therapist to teach you feeding intervention.

5. How did the therapist teach you this intervention? (Probing question may be needed).

6. Which method of teaching did you find most useful?

7. Did you participate in goal planning with the therapist for your child?

8. How would you spread the word about home care?

9. Do you have any other comments regarding your child's feeding?

APPENDIX C

Care Givers' Consent tp Participate

TEXAS WOMAN'S
UNIVERSITY
DENTON/DALLAS/HOUSTON

CARE GIVERS' PERCEPTIONS OF THE ROLE OF THE HOME CARE THERAPIST IN NON-ORAL FEEDING INTERVENTION IN FAILURE TO THRIVE PATIENTS

Care Givers' Consent to Participate in Research

I hereby authorize AUDREY BELL to interview me for the purpose of telling her about my child's feeding skills. The purpose of the research is to find out about how care givers feel about the home care therapist role in feeding intervention in Failure to Thrive patients. This research can lead to better and useful practice in the home setting. The interview will take place in my home or in a location that is convenient to me.

I will be interviewed only once for about 1-2 hours. I understand that the interview will be tape recorded, and that my name or my child's name will not be spoken at any time. The tape recording will be listened to and typed. These procedures have been explained to me in detail by the researcher.

I understand that the purpose of this study is to assist therapists who work in the home to consider recommendations that will lead to better understanding as to how to help care givers. This study may assist therapists who work with feeding intervention in deciding on the need for a specific treatment to lead to feeding by mouth.

I understand that the procedures that have been explained to me will involve the possible loss of confidentiality. My privacy will always be maintained by not having my name written on any report or speaking my name in any report. I will only be identified as a number. Risk of embarrassment will be eliminated by my not having to tell the interviewer any sensitive information. I know that I don't have to do so if I don't want to. I have been told that only the researcher will listen to the tape recording.

There are no direct benefits from my participation in this study. An offer to answer all of my questions regarding the study has been made, and all possible risks and discomforts reasonably to be expected have been explained. I understand that I may withdraw my consent or discontinue my participation in this study at any time without feeling intimidated or having anything held against me or my child.

I have been reassured that confidentiality of all records identifying me or my child will be maintained at all times. If I should have any questions concerning this research or my rights as an informant in this research, or in case of a research related injury, I may contact Audrey Bell, OTR at (713) 770-2403 or the Office of Research and Grants Administration during office hours at (817) 898-3375. I give my consent to this interview.

Carnestine Galloway
Informant's Signature

3/28/95
Date

TEXAS WOMAN'S
UNIVERSITY
DENTON/DALLAS/HOUSTON

CARE-GIVERS' PERCEPTIONS OF THE ROLE OF THE HOME CARE THERAPIST IN NON-ORAL FEEDING INTERVENTION IN FAILURE TO THRIVE PATIENTS

I consent to the recording of my voice by Audrey H. Bell, OTR, acting under the authority of the Texas Woman's University, for the purpose of the research project entitled "Care Givers' Perceptions of the Role of the Home Care Therapist in Non-Oral Feeding Intervention in Failure to Thrive Patients". I understand that the material recorded for this research will be kept in a locked file at Texas Woman's University. I understand that the information gained from this research will be made available for education, information and/or research purposes; and I hereby consent to such use.

Earnestine Dallaway
Informant

3/28/95
Date

The above form was read, discussed and signed in my presence. In my opinion, the person signing said consent form did so freely and with full knowledge and understanding of its contents.

Audrey Bell, OTR
Authorized representative
of Texas Woman's University

3/28/95
Date

TEXAS WOMAN'S
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Sheila Fusini
Informant's Signature

4-14-95
Date

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DENTON/DALLAS/HOUSTON

CARE-GIVERS' PERCEPTIONS OF THE ROLE OF THE HOME CARE THERAPIST IN NON-ORAL FEEDING INTERVENTION IN FAILURE TO THRIVE PATIENTS

I consent to the recording of my voice by Audrey H. Bell, OTR, acting under the authority of the Texas Woman's University, for the purpose of the research project entitled "Care Givers' Perceptions of the Role of the Home Care Therapist in Non-Oral Feeding Intervention in Failure to Thrive Patients". I understand that the material recorded for this research will be kept in a locked file at Texas Woman's University. I understand that the information gained from this research will be made available for education, information and/or research purposes; and I hereby consent to such use.

Sheila Fusini
Informant

4-14-95
Date

The above form was read, discussed and signed in my presence. In my opinion, the person signing said consent form did so freely and with full knowledge and understanding of its contents.

Audrey Bell, OTR
Authorized representative
of Texas Woman's University

4/14/95
Date

TEXAS WOMAN'S
UNIVERSITY
DENTON/DALLAS/HOUSTON

CARE GIVERS' PERCEPTIONS OF THE ROLE OF THE HOME CARE THERAPIST IN NON-ORAL FEEDING INTERVENTION IN FAILURE TO THRIVE PATIENTS

Care Givers' Consent to Participate in Research

I hereby authorize AUDREY BELL to interview me for the purpose of telling her about my child's feeding skills. The purpose of the research is to find out about how care givers feel about the home care therapist role in feeding intervention in Failure to Thrive patients. This research can lead to better and useful practice in the home setting. The interview will take place in my home or in a location that is convenient to me.

I will be interviewed only once for about 1-2 hours. I understand that the interview will be tape recorded, and that my name or my child's name will not be spoken at any time. The tape recording will be listened to and typed. These procedures have been explained to me in detail by the researcher.

I understand that the purpose of this study is to assist therapists who work in the home to consider recommendations that will lead to better understanding as to how to help care givers. This study may assist therapists who work with feeding intervention in deciding on the need for a specific treatment to lead to feeding by mouth.

I understand that the procedures that have been explained to me will involve the possible loss of confidentiality. My privacy will always be maintained by not having my name written on any report or speaking my name in any report. I will only be identified as a number. Risk of embarrassment will be eliminated by my not having to tell the interviewer any sensitive information. I know that I don't have to do so if I don't want to. I have been told that only the researcher will listen to the tape recording.

There are no direct benefits from my participation in this study. An offer to answer all of my questions regarding the study has been made, and all possible risks and discomforts reasonably to be expected have been explained. I understand that I may withdraw my consent or discontinue my participation in this study at any time without feeling intimidated or having anything held against me or my child.

I have been reassured that confidentiality of all records identifying me or my child will be maintained at all times. If I should have any questions concerning this research or my rights as an informant in this research, or in case of a research related injury, I may contact Audrey Bell, OTR at (713) 770-2403 or the Office of Research and Grants Administration during office hours at (817) 898-3375. I give my consent to this interview.

Audrey Bell
Informant's Signature

4/14/95
Date

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Jessie Ahmed
Informant

4/14/95
Date

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Audrey Bell, OTR
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Elaine Hime
Informant's Signature

4/20/95
Date

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Elaine Hime
Informant

4-20-95
Date

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Audrey Bell
Authorized Representative
of Texas Woman's University

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Sylvia McVaugh — 4/19/95

Informant's Signature — Date

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Informant — Date: 4/19/95

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Audrey Bell, OTR
Authorized representative
of Texas Woman's University — Date: 4/19/95