

BARRIERS TO DENTAL CARE FOR CHILDREN  
WITH SPECIAL HEALTH CONCERNS

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A THESIS

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IN THE GRADUATE SCHOOL OF THE

TEXAS WOMAN'S UNIVERSITY

COLLEGE OF HEALTH SCIENCES

BY

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To the Associate Vice President for Research and Dean of the Graduate School:

I am submitting herewith a thesis written by Joni R. Hopps entitled "Barriers to Dental Care for Children with Special Health Concerns." I have examined this thesis for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Master of Science, with a major in Health Studies.

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## DEDICATION

To the special parents and children at Texas Scottish Rite Hospital for Children.

## ACKNOWLEDGMENTS

With profound thanks to Dr. Eva Doyle for her willingness to provide guidance throughout the course of my graduate studies and specifically for her expedient return of thesis drafts allowing me to meet mandated deadlines. Also, I wish to convey deep appreciation to Drs. Susan Ward and Judy Baker for serving on my research committee and contributing their expertise toward design of the survey instrument--with special mention of Dr. Suzi Seale, who, despite her overwhelming schedule, allowed time for critique of the research questionnaire.

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## ABSTRACT

### COMPLETED RESEARCH IN HEALTH STUDIES

Texas Woman's University, Denton, Texas

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Children with special health concerns have been identified as being underserved in many areas including accessibility to dental health education and intervention. This pilot study was conducted to determine the barriers encountered by parents in accessing dental care for their children with special health concerns. A convenience sample of 20 parents was utilized in this investigation. Analysis of the data revealed that these parents (a) had received varying dental health information primarily identifying the source as a doctor/physician (34%), (b) had difficulties in the provision of dental care most commonly associated with their children's inability or unwillingness to clean their teeth (20%), (c) had encountered difficulties in accessing dental care for their children most often involving the expense of dentistry and the lack of dentists with training to treat children with special health concerns, and (d) suggested increasing financial resources directed toward pediatric dental care in conjunction with the greater availability of specially-trained dentists.

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## CHAPTER I

### INTRODUCTION

In an effort to prevent the subsequent problems of diseases associated with the oral tissues (caries, periodontal disease, etc.), dental professionals in conjunction with health educators have attempted to promote the dissemination of dental health information and accessibility to dental care. One particular population that has encountered barriers to this necessary component of health care are children with special health concerns. While multiple inhibitors have been suggested, current literature provides few studies related to the thorough identification of these interrelated elements affecting parental decisions on dental care.

#### Statement of the Problem

This pilot investigation was conducted in an effort to determine the barriers encountered by parents/legal guardians in accessing dental care for their children with special health concerns. This unique pediatric population has been identified as being underserved in many areas including accessibility to dental health education and intervention. Variables included within the research survey were age and diagnosis of the child as reported by his/her parent, descriptions of difficulties in providing dental care and accessing dental services, and delineation of parental suggestions on improvement of dental care accessibility.

### Purpose of the Study

Through utilization of a descriptive design, the purpose of this study was to identify those barriers that parents/legal guardians in the selected sample have encountered in providing and accessing dental health-related care for their children with special health concerns.

### Research Questions

The following questions were formulated to direct this pilot research project:

1. What types of dental health information have been provided to parents/legal guardians for their children with special health concerns?
2. What are the barriers encountered by parents/legal guardians in providing dental care for their children with special health concerns?
3. What are the barriers encountered by parents/legal guardians in accessing dental care for their children with special health concerns?
4. What are potential promoters to improving dental care accessibility for children with special health concerns as identified by their parents/legal guardians?

### Definitions

In order to clarify terms as used within this study, the following definitions are provided:

1. Barrier(s). A perceived obstacle or difficulty in obtaining dental care for their children as described by the parents/legal guardians on the questionnaire/interview.

2. Dental care. Examination and/or treatment of the teeth and associated oral tissues by a licensed dental professional.

3. Dental health information. Knowledge communicated or received concerning prevention or control of diseases of the teeth and supporting oral tissues.

4. Children with special health concerns. Any boy or girl aged infancy through 18 years that has been accepted for care at Texas Scottish Rite Hospital for Children.

Multiple terms such as handicapped, chronically ill, and disabled have been utilized by researchers to describe individuals with a limiting physical or mental impairment. For the purposes of this study, the sample was defined as parents/legal guardians of children with special health concerns. The data collection instrument allowed the parent to self-report on their child's medical diagnosis or problem versus accessing the confidential medical record. Utilizing more rigidly defined terms such as chronically ill or disabled may have excluded some subjects unable to adequately describe their child's impairment in appropriate medical terminology. While special health concerns had limited applicability in searches of national data banks for related material this researcher was able to reference the term disabled which, in fact, encompasses the special pediatric population being sampled. Henceforth the terms special health concerns and disabled will be used interchangeably.

### Limitations

Limitations influencing the generalizability resulted from selection of a convenience sample. Parental responses in enumerating barriers to dental care may have been impacted by the scope and frequency of past experiences leading to some variability.

### Delimitations

Drafting this study design led to the establishment of certain delimitations in reference to sample selection. Only parents/legal guardians of patients at Texas Scottish Rite Hospital for Children were included and their participation was strictly voluntary. The sample selected was additionally defined as being English-speaking.

### Significance of the Study

Early dental health education and intervention may reduce the prevalence of dental disease among all children, including those with special health concerns. Healthy People 2000 oral health objectives target reduction of dental caries as part of the initiatives for school-age and adolescent children (U.S. Department of Health and Human Services [USDHHS], 1993). Yet, barriers to dental care for children with special health concerns may lead to the postponement or the total lack of this necessary health care component. Identifying these barriers would provide information for health educators and dental providers as they plan programs promoting dental health within this special pediatric population.



## CHAPTER II

### REVIEW OF LITERATURE

Dental health is an important component of the overall health profile of the general population. Children, in particular, can be shielded from the severities of dental disease when appropriate preventive measures are implemented. National epidemiologic surveys in the 1970s and 1980s have been interpreted to indicate a major decline in dental decay among children aged 5 to 17 years (Mandel, 1996). While this trend would appear encouraging, further examination of the data reveals that 20 % of the children suffer from 60 % of the decay (Klein et al., 1985). Thus, a minority of children in those studies still suffered unacceptably high levels of decay (Brown, 1994).

Lack of equal access to dental care and potential variations in individual susceptibility may contribute to this unequal caries distribution pattern. It has been widely reported in dental journals that handicapped persons have difficulty obtaining dental treatment with multiple factors involved in this restricted access (Brown, 1980). Children with special health concerns, in addition to facing the aforementioned accessibility limitations, have also been linked to risk factors associated with nursing bottle syndrome and caries resulting from frequent intake of syrupy medications (Muller, 1996; Roberts & Roberts, 1981). Findings would suggest that this special pediatric population may be a segment of the sample of children for which dental disease remains a significant problem.

### Children with Disabilities

Within a 1991-92 Department of Commerce Bureau of Census report the term disabled was fully delineated. Denoted in the report, under childhood disabilities, was inclusion of the following health conditions: asthma, autism, blindness or vision problems, cancer, cerebral palsy, deafness or serious trouble hearing, diabetes, drug or alcohol problems or disorders, epilepsy or seizure disorders, hay fever or other respiratory allergies, head or spinal cord injury, heart trouble, impairment or deformity of back, side, foot or leg, impairment or deformity of fingers, hands or arms, learning disability, mental or emotional problem or disorder, mental retardation, missing legs, feet, toes, arms, hands, or fingers, paralysis of any kind, speech problems and repeated ear infections (Department of Commerce Bureau of the Census, 1993).

According to census data within the aforementioned 1991-92 report, there were more than 3.9 million disabled children residing in the United States. This figure representing approximately 5.8 % of all children less than 18 years of age (Department of Commerce Bureau of the Census, 1993). Of that population, there were more than 3.1 million white, 0.6 million black, and 0.3 million Hispanic disabled children. Boys have a somewhat higher disability rate than girls with both genders experiencing a progressive disability rate increase with age (Waldman, 1995). Of concern to health educators, as well as health providers, is the fact that this special pediatric population faces unique health concerns, of which, oral health cannot be excluded.

### Oral Health/Etiology of Dental Disease

Children with special health concerns will most likely have a multiplicity of medical, nutritional, and emotional needs throughout their lifetime. A question arises concerning the importance of the oral cavity in the child's total health picture and quality of life. Teeth that are intact and without dental caries will allow better chewing capability that provides maximal nutrition and dietary intake. Through maintenance of appropriate hygiene for supporting oral tissues (e.g., gums or gingiva, tongue, mucosa), a potential source of infection, irritation, and halitosis might be eliminated (Bhaskar, 1977). The disabled child with healthy-looking teeth will also have a greater sense of well-being, leading to the likelihood of an improved self-image.

Do children with special health concerns inherently possess any risk factors increasing susceptibility to dental disease? Investigation of dental disease generally involves two major categories, caries (dental decay) and periodontal disease (gum disease). While affecting different oral tissues, both caries and periodontal disease involve microorganisms, a susceptible host, and a conducive environment. Dental caries is described as the process occurring when the enamel is demineralized by organic acids that are produced locally by bacteria. Plaque, a sticky gelatinous film containing bacteria, mucus, desquamated cells, and food debris, adheres to the surfaces of teeth and is involved in the development of caries. This same plaque, which may lie in the vicinity of the gingival (gums) sulcus, is also implicated in the etiology of gingival lesions, which

are precursors to periodontal disease (Bhaskar, 1977). Thus, removal of this plaque would seem paramount in preventing dental disease.

Bhaskar (1977) included the following when discussing factors that may predispose one to the development of caries: species, civilization, heredity, diet, composition and physical form of teeth, oral hygiene, and saliva. Diet and oral hygiene have traditionally been targeted by dental providers and health educators as areas for dental health promotion. Children with special health concerns may or may not be able to take advantage of the dental health recommendations on dietary and hygiene modifications. These children may have prescribed diets including a regimen of medications that have cariogenic properties, but cannot be altered due to overall health needs.

Prolonged bottle-feeding along with chronic ingestion of sugar-based medications has the potential to significantly affect the rate of caries in an infant/child (Roberts & Roberts, 1981). In reporting on children with nursing-bottle syndrome, Muller (1996) noted 28.26 % of the affected children involved in his study had been or were still handicapped by an incapacitating morbidity, which may have led the parents to provide oral pleasure (extended use of bottle feeding), to compensate for the pain or discomfort. In evaluating nursing caries among a population of Dutch children, reports indicated that caries children had been sick more often (Everdingen, Eijkman, & Hoogstraten, 1996).

Oral hygiene may be compromised for children with special health concerns. The term disabled implies some impairment that restricts or limits activity, thus leading one to

conclude that the disabled child may be inherently disadvantaged and unable to accomplish even simplistic oral hygiene practices. Cognitive skills (reasoning, memory, logic) as well as motor skills may be affected as a result of a child's limiting impairment leading to an inability to fully comprehend explanations related to the etiology of dental disease. In an effort to motivate the child and/or parent/caretaker to adopt appropriate dental care habits, one may be required to provide more involved instructions including child-specific oral hygiene adaptations (Tesini & Fenton, 1994). Although, mastering these new skills either by parent or child may be considered too time-consuming.

#### Prevalence of Dental Disease

Determination of dental disease prevalence among disabled children on a national level has not been reported (Waldman, 1989) most probably due to the difficulties of establishing a target population for sampling when one must account for the multiple health conditions associated with childhood disabilities. Sampling various subsets of the handicapped pediatric population by disease/disorder classification has produced some limited data on oral disease. Researchers in one study (Hallett, Radford, & Seow, 1992) chose to sample children with congenital heart disease, a condition listed within the United States Bureau of Census definition of a disabled child. Findings suggested that these particular children suffer poor oral health as compared with control children involved. Researchers (Pope & Curzon, 1991) reporting on the dental health status of cerebral palsied children noted that the mentally handicapped study children had fewer sound teeth than those without mental handicap. Analysis of the data collected on the

sample population led to the conclusion that the cerebral palsied children had more unrestored carious primary teeth, more unerupted teeth, fewer filled, and more missing teeth. In contrast, Brown (1980) suggested that a review of prevalence data indicated caries is not significantly different for children with disabilities as compared to normal children, though frequently periodontal disease was more widespread.

While there appears to be a paucity of established quantifiable data on dental disease prevalence within the general community of disabled children residing in the United States, published information suggests that oral health is a significant concern for this population. At issue is the realization that both dental caries and periodontal disease are preventable and controllable (Gift, Corbin, & Nowjack-Raymer, 1994). With effective and fairly inexpensive preventive measures in existence, logical reasoning would suggest that more attention be directed toward oral care for the child with special health concerns.

### Barriers to Dental Care

Previous discussion detailed potential physical barriers to the provision of dental care for children with special health concerns suggesting the need for modification of standard oral hygiene practices. When faced with the multiple needs of a severely handicapped child, some parents/caretakers may be overwhelmed and simply neglect any type of dental care (Brown, 1980). With many disabled children unable to participate in the provision of their own oral hygiene, external support such as from the parents/caretakers must be provided. Methods of presentation, time involved in

mastering the proposed skills, and education/knowledge level may affect how receptive parents/caretakers and/or the child are to any proposed recommendations.

In citing previously published materials, Hansel (1983) noted that criticism had been leveled against the dental team for failing to take into consideration the patient's total environment, including family, economic status, living conditions, nutritional status, history, and education when addressing the complexities of prevention and oral disease. Reporting on the low levels of knowledge regarding oral disease symptoms and their prevention, Gift et al. (1994) noted that, "Racial and ethnic minorities and groups with low levels of formal education demonstrate the least knowledge of prevention of oral diseases" (p. 397). And while providing information alone is not adequate to improve health, decisions about appropriate health behaviors will be difficult without sufficient knowledge of disease etiology and preventive strategies.

The fact that dental disease can exist without the child complaining of pain or discomfort should be stressed. Lo, Soh, Vignehsa and Chellappah (1991) concluded that the assumption that "nothing was wrong" seemed to be the major barrier to the regular use of dental services for the sample of disabled children involved in their study. Because 77% of the parents thought there was nothing dentally wrong with their children, one could reasonably assume that there was not a perception of dental need. Lo et al. suggested that an increased level of awareness should be created among the parents.

This attempt to increase dental knowledge among parents of children with special health concerns should also include information relative to advancements in delivery of

dental treatment. Many parents have memories of painful dental visits leading them to avoid such an experience for their own children (Lo et al., 1991). Dental technology has allowed for improvements providing for more comfort during dental care and this information should be conveyed to the parent/caretaker.

Prevention may necessitate home-based oral hygiene care, but reinforcement and support from healthcare providers in conjunction with dental professionals is also required. Sanger (1977) noted a need for greater integration of the medical and dental professions in implementing dental prevention programs for the infant. Dental health education and promotion must involve a multi disciplinary approach with open communication among the designated care providers. The roles of the various professionals may intersect and overlap in an effort to provide optimum care. Shared responsibility of the needs of the child with disabilities should include evaluating and seeking dental care resources at an early age for these children and their parents/caretakers (Williams & Fairpo, 1984).

The necessary resources must be available and accessible for the disabled child once a need is established. Dental care for the disabled child may involve some additional accommodations in the dental office (Tesini & Fenton, 1994). Their ability to tolerate treatment may be directly related to the complexity of their medical compromise. Many dental professionals may be reluctant to open their offices to this clientele for multiple reasons. Lack of formal training in dealing with the handicapped, further expense in obtaining necessary patient management adjuncts, and the increased liability



of treating a medically-involved patient are among the factors suggested by Tesini and Fenton for hesitation in providing care to the disabled.

Lack of accessibility to trained professionals may be the initial barrier to dental care but, once overcome, a secondary obstacle emerges. Are there available resources to cover the expense of dental intervention for the special needs child? Income may be viewed as a restrictive factor in the use of health services (Swank, Vernon, & Lairson, 1986), with insurance coverage of preventive dental services limited. When family financial resources are insufficient, the federally mandated Early Periodic Screening, Diagnosis, and Treatment Program (EPSDT) may be of assistance. As an amendment to the Title XIX Social Security Act of 1967, EPSDT was initiated as a federal-state medical assistance program for improving access to health care for poor children. One of the services covered in this comprehensive preventive health program is dental care. Medicaid-eligible disabled children would be able to take advantage of this funding source (Chauvin & Davis, 1994).

Provision of resources, though, does not necessarily lead to utilization. A literature review by Richardson, Selby-Harrington, Krowchuck, Cross, and Williams (1994) revealed that, after 20 years of EPSDT implementation, conclusive data are not available to determine if EPSDT is improving the health of poor children. According to information gathered by Chauvin and Davis (1994), only 31-37% of all eligible children are receiving EPSDT services. The U.S. Department of Health and Human Services has encouraged greater EPSDT participation by the establishment of goals for all states.

Delay in seeking early dental intervention for children with special health concerns has the potential for generating even greater expense if comprehensive operative treatment becomes necessary. Inability to cooperate in conjunction with complex medical histories necessitate that much of the dental treatment provided for the disabled child be performed utilizing sedation or general anesthesia (Sheehy, Hirayama, & Tsamtsouris, 1994). Ongoing preventive dental services may be substantially less expensive than the cost of extensive operative needs which, in addition, may have an increased associated medical risk.

#### Dental Health Promotion

Tesini and Fenton (1994) in reviewing the oral health needs of persons with physical or mental disabilities have suggested that “There is no other group in which the need for prevention is greater. Primary prevention, before the development of disease, should be the single most important dental objective for children with developmental disabilities “ (p. 484). The American Academy of Pediatric Dentistry (AAPD), in evaluating infant oral health needs, has recommended that “a postnatal oral evaluation visit should occur within six months of the eruption of the first primary tooth and no later than twelve months of age” (Casamassimo, 1995, p. 26). This visit would provide an opportunity for preventive education and dental care to lay the foundation for optimal oral health into childhood.

Although this AAPD recommendation seems to promote the ideal preventive plan advocated by health educators, commitment among pediatric dental practitioners seems to

vary. Following a survey of Texas pediatric dentists, Kendrick, McWhorter, Seale, and Simpson (1996) concluded that disparity exists between the AAPD recommendation for the time of first visit and the personal beliefs and practices of component society members. Three-fourths of those members reporting stated that they see patients after age 1 year versus by the recommended “no later than 12 months of age”. Slightly more than two-thirds (68.8%) of those dentists surveyed indicated an agreement with the AAPD recommendation. For the one-third (31.2%) reporting disagreement, written comments indicated that the majority believed 12 months was too early.

In spite of controversy within the dental profession, consideration of the multifold needs of children with special health concerns would seem to indicate that provision for early dental intervention and education be considered a priority. In an effort to enable maximal benefits for the child with disabilities, dental health promotion must involve the formulation of a planned approach to increase awareness of the dental needs of these particular children. With evidence suggesting that this necessary component of health care continues to be neglected, further research directed toward exploring the existing barriers as encountered by parents/caretakers seems to be indicated.

Difficulties in providing and accessing dental care have been repeatedly reported by the parents/caretakers of those children with special health concerns treated in the dental clinic at Texas Scottish Rite Hospital for Children (TSRHC) in Dallas, Texas. This institution serves the children, aged infancy through 18 years, throughout the state of Texas who necessitate intervention related to musculoskeletal deformities resulting from

birth defects, accidents and diseases (Arena, 1995). Severity of sequelae noted with specific disorders vary among the pediatric patients from only slight physical limitations to total body involvement. In an effort to treat the whole child, the TSRHC care providers include assessment of the patient's supporting physiologic systems (including feeding issues related to the oral cavity) while focusing on the need for any orthopaedic intervention. Parents/caretakers of these children with special health concerns have utilized this opportunity to describe obstacles related to dental health issues for their children.

It is the purpose of this investigation to delineate those barriers encountered by the parents/caretakers through use of a questionnaire of utilizing both qualitative and quantitative items followed by a personal interview. Examination of the following variables are to be included in this study: (a) types of dental health information provided to, (b) barriers encountered in providing dental care by, (c) barriers encountered in accessing dental care by, and (d) identification of potential promoters to improving dental care accessibility as reported by parents/caretakers of children with special health concerns. It is hoped that a contribution to the field of dental health promotion can be made through determination of these barriers and that this information may be utilized by health educators/dental providers as they plan programs directed toward this special pediatric population.

### CHAPTER III

#### METHODOLOGY

The methodology selected for this study was descriptive in nature utilizing both quantitative and qualitative data collection approaches. Qualitative data is commonly gathered when conducting a pilot research project and is well-suited for process-oriented, smaller investigations (Robinson & Neutens, 1987). Improved understanding of the feelings, beliefs, and motives behind people's behavior is sought by qualitative researchers (Stainback & Stainback, 1988). The focus is on the viewpoint of individuals (subjective data) versus a collection of "hard" facts and numbers. Valuable insight can be gained through qualitative projects leading to improved construction of questionnaires and methodology for development of larger-scale quantitative studies.

Further discussion in this section will involve a description of the population and the procedures used to sample the population. The instrument utilized in measuring the variables along with the procedures used to collect the data will be detailed. Data were analyzed in accordance with the qualitative nature of the design.

#### Population and Sample

The setting for this study was Texas Scottish Rite Hospital for Children (TSRHC), a privately funded pediatric hospital located in Dallas County. The hospital has approximately 11,000 active patient files. This institution serves children from infancy

through 18 years of age throughout the state of Texas who require treatment related to musculoskeletal deformities resulting from birth defects, accidents, and diseases. Having been diagnosed with one or more of these special health concerns is a requirement for application and treatment at TSRHC.

A convenience sample of 20 subjects was drawn from the population of parents/legal guardians accompanying new patient referrals to the Dental Clinic at TSRHC. Each patient was described as having special health concerns, a requirement for admission to TSRHC. The parents participated on a voluntary basis with assurance that there would be no negative repercussions if they declined to take part in the research. To control for potential bias introduced by language influences, sample recruitment was limited to English-speaking participants.

### Procedures

The guidelines of the Texas Woman's University Human Subjects Review Committee (HSRC) were applied in this study. Formal consent from the subject was not required, but implied upon completion of the research instrument. Only group data was reported without the utilization of any names to protect the confidentiality of the participating subjects. In compliance with research guidelines, written approval was obtained from the Texas Woman's University HSRC (Appendix A) along with a letter of agency cooperation from TSRHC (Appendix B).

Subject recruitment was initiated on January 21, 1997, and continued over a 4-week interval. Upon arrival for their children's initial dental appointment, the

parents/legal guardians were asked by the researcher to complete the instrument (questionnaire) while their children awaited treatment. Following completion of the questionnaire, the subjects were interviewed in an adjoining room (or remained in the waiting room if no other families were present) to clarify their responses. Approximate time allocated for completion of the questionnaire and the personal interview was 15 to 20 minutes.

### Instrumentation

The questionnaire entitled Dental Health Questionnaire ( see Appendix C) was developed by the principal investigator to gather descriptive information that measures the frequency and types of barriers encountered in the provision of and accessibility to dental care within the sample. Demographic information solicited on the questionnaire included parents/legal guardians' language preference, their children's date of birth, and a description of their children's diagnosis or medical problem. The instrument was composed of both structured questions (7 items) and open-ended questions (4 items). Dental information, dental information sources, difficulties in provision of dental care, and experiences with professional dental care were the focus of the structured items. Open-ended items asked parents to describe: (a) the greatest difficulty encountered in caring for their children's teeth, (b) specific problems encountered during their children's dental visit, (c) the greatest difficulty encountered in finding professional dental care for their children, and (d) how the availability of dental care for their children could be improved.

In collecting qualitative data, the investigator is concerned less about data reliability and prefers rather to concentrate on validity, data that represent a true or full picture of what the researcher is investigating (Stainback & Stainback, 1988). In an effort to assure validity of the untested instrument, three health educators with expertise in qualitative questionnaires and two pediatric dental professionals with experience in caring for children with special health concerns were asked to evaluate the questionnaire for content validity. Two weeks were allowed for response by the reviewers. All suggestions were considered and changes made based on panel consensus.

Three parents were selected from within the sample population to evaluate the questionnaire for understandability, format, and language-appropriate questions. Each comment was considered and revisions incorporated within the instrument prior to final submission to the expert panel.

Further testing of readability was performed with the assistance of Gramatik, a computerized program that utilizes the Flesch-Kincaid formula to compute the school grade level required for the reader to understand the text (Mailloux, Johnson, Fisher, & Pettibone, 1995). A grade level score of 6-10 is considered the most effective for a general audience. The final draft of the Dental Health Questionnaire received a score of 8.14.

#### Treatment of Data

Basic demographic characteristics were reported using descriptive statistics of frequency and percentage, as applicable. The remaining qualitative data were coded to



facilitate the development of a process-oriented matrix. Further data analysis included organization, classification, and categorization of information denoting any patterns or missing information requiring further research. To broaden insight into the views and feelings of the subjects, anecdotal responses were reported where indicated.

## CHAPTER IV

### FINDINGS

In this study, a descriptive approach was used to analyze issues related to dental care for children with special health concerns as identified by their parents/legal guardians. Collection of data was accomplished by means of participant completion of the Dental Health Questionnaire (Appendix C) and a subsequent interview. Methods of analyzing data were described in Chapter III. Organization of data coincided with the theme questions denoted on the instrument. Those were the provision of dental health information, provision of dental care, accessibility of professional dental care, and suggestions for improving dental care availability. A description of the sample is presented, followed by delineation and categorization of the responses associated with the concerns under review.

#### Description of Sample

The sample consisted of 20 parents of children with special health concerns attending the Texas Scottish Rite Hospital for Children (TSRHC) Dental Clinic for a new patient examination during the 4-week data collection period. All subjects preferred English as their primary language. Children of the sample varied in age from 2 to 16 years with a mean of 4.6 years. A summary of the variable of age is presented in Table 1.

Table 1

Frequency Distribution and Percentages of the Subjects' Children's Age (years)

Value	Frequency	Percent
2	2	10.0
3	5	25.0
4	2	10.0
5	1	5.0
6	1	5.0
8	1	5.0
9	1	5.0
12	2	10.0
13	2	10.0
14	2	10.0
16	1	5.0
	<hr/> 20	<hr/> 100.0%

Frequency and distribution related to the medical diagnoses of the subjects' children are reported in Table 2. The subjects were asked to self-report their children's special health concerns in lieu of accessing confidential medical records. As Table 2 denotes, similar descriptions were clustered for the purpose of interpretation. Nine different diagnosis clusters were reported within the group with cerebral palsy being the most frequently mentioned (30%).

Table 2

Frequency Distribution and Percentages of the Subjects' Children's Diagnosis

Value	Frequency	Percent
Cerebral Palsy <sup>a</sup>	6	30.0
Spina Bifida tethered spinal cord	4	20.0
Bleeding on the brain when born something in the brain stem brain damage/lack of oxygen	3	15.0
Neurofibromatosis questionable neurofibromatosis	2	10.0
Autism	1	5.0
Developmental Delay (pervasive)	1	5.0
Mixed Connective Tissue Disorder	1	5.0
Tourette's Syndrome	1	5.0
Vitamin D Resistant Rickets	1	5.0
	<u>20</u>	<u>100.0%</u>

<sup>a</sup> Two subjects reported seizure disorder as a secondary diagnosis to cerebral palsy

Provision of Dental Health Information

The sample was asked to identify the types of dental health information they had acquired. Response choices ranged over eight information categories with the inclusion

of options to further describe other information or to note that none of the selections provided were appropriate. Subjects were requested to check all applicable responses. Frequency and distribution of answers are detailed in Table 3. Brushing methods (19%), age to initiate professional dental care (19%), teeth eruption patterns (16%), and the need for fluoride (14%) were the responses selected most often.

Table 3

Frequency Distribution and Percentages of Subject Responses to Type of Dental Information Provided for their Children

Variable	Frequency	Percent
Ways to brush the teeth	11	19.0
Age your child should see a dentist	11	19.0
When the teeth should appear (erupt) in the mouth	9	16.0
The need for fluoride	8	14.0
Age to limit or quit using the nursing bottle	6	11.0
How medications might affect the teeth or gums	4	7.0
None of the items listed	4	7.0
How to manage oral habits	2	3.5
Care of the teeth if child is fed through stomach or G-tube	2	3.5
	<u>57</u>	<u>100.0%</u>

To determine dental health information resources used by the sample, the subjects were asked to denote the source(s) of their previously described dental facts. The doctor (34%), the dentist (20%), and the nurse (13%) were the most frequent providers of dental health information. One subject reported receiving none of the listed dental health information items, but noted dental health information had been provided by a teacher and through viewing television. “Own background” and “experiences with older siblings and child care books” were described as resources by two subjects in the “other” category. Further information on the pattern of answers is provided in Table 4.

#### Provision of Dental Care

Dental care requires significant participation by the parent/caretaker in order to accomplish the goal of preventing dental disease. The subjects were asked to identify any difficulties that they may have encountered in providing dental home care for their children with special health concerns. The question provided eight response choices about the provision of dental care including options to indicate none of the selections were appropriate and to describe other concerns. The participants identified the children’s unwillingness to or inability to cooperate for tooth brushing (20%), other issues related to difficulties in brushing (20%), and the children swallowing the toothpaste (17%) most frequently. The frequency and distribution of responses is delineated in Table 5.

Table 4

Frequency Distribution and Percentages of Subject Responses to Source of Dental Health Information

Variable	Frequency	Percent
A doctor/physician	10	34.0
A dentist	6	20.0
A nurse	4	13.0
None of the items listed	3	10.0
A dental hygienist	2	7.0
Other	2	7.0
Newspaper or magazine article	1	3.0
Television	1	3.0
A teacher	1	3.0
	30	100.0%

For many subjects, difficulty in the provision of dental home care arose simply because their children “did not want to brush.” This situation was experienced by those parents solely responsible for the children’s care and also where the children were capable of performing their own oral hygiene tasks. Responding to the selection labeled “other--

describe,” subjects reported the following: “doesn’t brush unless told to do so, doesn’t like to [brush] after shown how, thinks it is a game and bites down, doesn’t brush them enough, jaw muscles are tight and hard to get into mouth, and very oral defensive.”

Table 5

Frequency Distribution and Percentages of Subject Responses to Difficulties in the Provision of Dental Care for their Children

Variable	Frequency	Percent
Child does not (or is unable to) cooperate for brushing	6	20.0
Other	6	20.0
Child swallows the toothpaste	5	17.0
Fear of hurting my child during brushing/cleaning mouth	4	13.0
Unsure how to brush/clean mouth properly	3	10.0
None of the items listed	3	10.0
Child does not like the toothpaste	2	7.0
Cleaning teeth/mouth takes too much time	1	3.0
	30	100.0%

In an open-ended question requesting that the greatest difficulty in providing dental care be described, the following responses were recorded: “Sometimes she falls asleep in evening before I get to brush her teeth.”, “Making sure food is out of his mouth



after meals--he used to store in his mouth--difficulty getting out--now we get him to spit it out.”, and “Question as to how to take care of her teeth due to her swallowing dysfunction and her oral defensiveness.”

#### Accessibility of Professional Dental Care

While much of the prevention of dental disease is dependent upon daily oral hygiene habits performed in the home, the dental professional should be sought to determine the existence of any oral abnormalities/disease and as a guide to the provision of the best possible personal dental care. Educational information related to ongoing changes in the oral structures of the pediatric population can be extremely valuable in preventing unnecessary and costly dental intervention. The subjects were asked if their children had been seen by a dentist or been to a dental clinic in their community. There were nine positive responses (45%), while eleven subjects (55%) reported that their children had not been to a dentist before visiting the Dental Clinic at TSRHC.

Of the nine subjects recording a positive response, additional questions were provided to determine whether efforts would be made to return to the same dentist/facility and what type experience they/their children had encountered. Only five (56%) of the nine subjects reported the dental visit as being a positive experience. The frequency and distribution of selection of the six response choices related to returning to the same dentist/facility are provided in Table 6. “Other” responses included: (a) physician suggested seeing another dentist, (b) moved to another area, (c) child was seen at sibling’s dentist and told they were too young with the need for special equipment. None of the

subjects selected the item stating “not return to the dentist because they suggested your child see someone else.”

One parent, while indicating the experience was positive, described the following problem encountered during his/her child’s visit, “treatment room was small, hard to get . . . in and out of dental chair.” Indication that the visit was not positive was denoted by four of the nine subjects (44%), with the following descriptions included by two participants: “He [the dentist] pulled one tooth, but suggested seeking dental assistance by someone experienced in treating gum problems due to medication in children.” and “. . . is very hyperactive, won’t sit still, won’t open her mouth for dentist.”

Table 6

Frequency Distribution and Percentages of Subject Responses to Returning with their Children to the Same Dentist/Facility

Variable	Frequency	Percent
Other	3	34.0
Return to the dentist for regular dental care	2	22.0
Not return to the dentist because dental treatment cost too much	2	22.0
Return to the dentist for emergency care only	1	11.0
Not return to the dentist because you/your child were (was) not happy with the care received	1	11.0
	<u>9</u>	<u>100.0%</u>

Subjects were asked to describe any difficulties they may have had in finding dental care for their children if they responded negatively to the survey question on a previous professional dental visit. A multiplicity of answers were provided for selection with the inclusion of an option to describe any specific difficulty encountered not previously delineated. Responses included in the “other” category were recorded as follows: “knew it was around 3 yrs. old so didn’t think it was time, did not need services at that time, fear and worry about his getting put to sleep, and oral defensiveness.” Table 7 provides the frequency and distribution of responses related to accessing dental care.

In an open-ended format, the subjects were requested to further elaborate on their greatest difficulty in finding dental care for their children, the following responses were disclosed: “I did not have trouble. I just asked at her SRH [Texas Scottish Rite Hospital for Children] appt. checkup and was sent info (sic) from the dental clinic.”, “I haven’t really had to search since Scottish Rite has offered its services.”, “Didn’t realize Scottish Rite had dentist.”, “Dentist fees.”, “No insurance and in our home town you tell them she’s allergic to latex it flips them out.”, and “ Some dentist don’t take special needs children.”

Table 7

Frequency Distribution and Percentages of Subject Responses to Difficulties in Accessing Professional Dental Care

Variable	Frequency	Percent
Other	4	21.0
No dental insurance coverage for my child	3	16.0
Dentist contacted does not see children w/ special health concerns	3	16.0
Dental care too expensive	2	10.5
Dentist contacted does not see children	2	10.5
Not a specialized (pediatric) dentist in my community	2	10.5
None of the items listed (haven't attempted to access dental care)	2	10.5
Dental care not needed--child has no problem with teeth	1	5.0
	<u>19</u>	<u>100.0%</u>

Suggestions for Improving Dental Care Availability

At the conclusion of the questionnaire, subjects were given the opportunity to recommend up to three ways to improve the availability of dental care for their children. Seven of the participants elected to complete this portion of the instrument of their own accord, while the remaining majority were prompted to respond during the interview. Those subjects recording recommendations prior to being interviewed made the following

suggestions: “If the dentist office was wheelchair friendly.”, “Healthy teeth, notification if there are any problems.”, “By coming here [TSRHC] and her brushing at least twice a day.”, “Knowledge of special needs children, less money, and covered fully by insurance.”, “Reminder about appointments.”, “If there was a dentist in our area that was known for dealing with children that are very oral defensive.”, and “Give suggestion on brushing teeth, . . .need teeth clean, . . .has silver filling.”

The majority of those subjects questioned in reference to any suggestions for improving dental care availability for their children mentioned the need for dentists trained to care for children with special health concerns and resources to assist with the fees involved in dental care. One respondent noted that typical financial resources (e.g., Medicaid, etc.) were unavailable to his/her child because the child was not an American citizen. Several participants had no recommendations since they had made no attempt to access dental care and, thus, were unaware of the need for any improvements.

### Summary

In this chapter, results of descriptive statistics have been reported for the demographic data of children with special health concerns and parental responses on the Dental Health Questionnaire. Anecdotal comments integrated throughout the findings were solicited through the inclusion of open-ended questions on the instrument with further clarification provided during the interview. Descriptive statistics demonstrated that the age of the children of the sample ranged from 2 to 16 years with a mean of 4.6 years.

While the sample reported nine different diagnoses for their children, the majority were identified as having cerebral palsy.

The primary responses in reference to the type of dental health information provided involved brushing methods and age for initial dental visit with 34% reporting that a doctor/physician furnished the dental education. The most commonly reported difficulty in the provision of dental care was the children's unwillingness or inability to cooperate for brushing (20%). The majority of the sample (55%) reported that their children had not been seen by a dentist with most of these participants noting that they had not yet attempted to access professional dental care. Additional difficulties denoted in finding dental care included the expense and lack of dentists with training to treat children with special health concerns. For those subjects (45%) noting that their children had been to a dentist, only 22% reported a willingness to return to the same dentist for regular care.

The subjects provided minimal responses when asked to describe ways for improving the availability of dental care. Suggestions primarily involved increasing the resources to cover the fees of dental care and increasing the number of dentists trained to treat children with special needs. These data indicate that parents were able to identify and describe barriers to dental care for their children with special health concerns.

## CHAPTER V

### SUMMARY OF THE STUDY

The purpose of this study was to identify those barriers that parents/legal guardians in the selected sample have encountered in providing and accessing dental health-related care for their children with special health concerns. A review of the significant literature, the procedure for data collection, and data analysis have been discussed in the previous chapters. This chapter summarizes the study, discusses findings, identifies implications for dental health educators/professionals, and makes suggestions for further study.

#### Summary

The setting for this study was Texas Scottish Rite Hospital for Children (TSRHC), a moderately-sized, not-for-profit facility, located in Dallas, Texas. This institution provides services for those children necessitating intervention related to musculoskeletal deformities resulting from birth defects, accidents, and diseases. During the assessment phase of entry, the TSRHC primary care provider may also evaluate dental health needs leading to a referral to the in-house Dental Clinic. The parents of these new patient referrals were recruited as subjects for this study.

This study used participant completion of the Dental Health Questionnaire (Appendix C) and semi-structured interviews to evaluate the barriers to dental care

encountered by parents of children with special health concerns. The responses of the sample were described and analyzed with specific feedback identified through the use of anecdotal comments. Descriptive statistical analysis of the data involved reporting on the frequencies, distribution, and percentages of the subjects' responses related to the provision of dental health information, provision of dental care, accessibility of professional dental care, and suggestions for improving dental care availability for their children. Demographic data collected indicated the ages and primary diagnoses for the children as described by the sample.

#### Discussion of Findings

The results of the study indicate that the subjects are able to identify barriers to dental care for their children with special health concerns. Those obstacles encountered varied among the delineated categories: dental health information, provision of dental care, and accessibility of professional dental care. In spite of the inundation of dental health information available through contact with healthcare providers, the media, printed material, and personal experiences, 4 of the 20 subjects reported having received none of the basic pediatric dental facts described on the instrument.

Glanz, Lewis, and Rimer (1990) conclude that "One of the axioms of health education is that knowledge is necessary but not sufficient for behavior change. Information is necessary but not sufficient for knowledge (p. 148)." This concept correlates with the postulates of the Consumer Information Processing Theory (CIP). In this study, those subjects already having acquired information related to dental care for



their children may still not have the knowledge and/or the capability to effect dental behavior decisions appropriately. In contrast, those subjects claiming an absence of any dental information illustrate a population that lacks even the basic cornerstone of healthcare decision-making.

There seemed to be a consensus among the sample indicating difficulty in toothbrushing as a barrier to the provision of dental care. The subjects reported that their children were either unwilling or unable to cooperate in this basic oral hygiene task. A possible influencing factor may be varying levels of parental caregiving skills especially in gaining a child's cooperation. Other responses denoted concerns related to toothpaste ingestion, fear of harm to child during brushing, and uncertainty of proper brushing technique. This information should be part of the material imparted to parents/caretakers during the American Academy of Pediatric Dentistry's (AAPD) recommended early childhood dental screening (Casamassimo, 1995). A doctor/physician may not have the background to provide complete explanations and demonstrate brushing/cleaning mouth techniques specific to this needs of this sample, and, yet, the subjects reported the physician as the chief contributor of dental health information. It seems apparent that if parents look to the primary care provider for assistance in dental health matters then improved dental education should be made available for these healthcare personnel. In addition, healthcare practitioners should be encouraged to consistently make early childhood referrals to appropriate dental professionals.

An additional assumption of CIP is that individuals have a limited capacity for processing information and may not seek all of the relevant data on a given health issue. With this fact in mind, literature has suggested that health educators become proactive in assuring the quality of disseminated health information (Glanz et al., 1990). A majority of the sample involved in this research project indicated that a doctor/physician had provided dental health facts related to their children. It is interesting to note that for those subjects indicating that their children had experienced a professional dental visit (45%), two did not list the dentist as a source of dental health information, but selected the doctor and television/teacher as the information providers. This study did not endeavor to determine either the quality or accuracy of the dental care information acquired by the sample.

Less than half of the sample (45%) had actively sought professional dental services for their children. Of those subjects, only two reported that they would return to the same dentist for regular care. These two subjects, while indicating that the dental visit was a positive experience, also described problems during their encounters. The explanations provided were related to the space limitations in the office physical structure and a poor experience for their child during the extraction of a tooth. The resulting sequela associated with the diagnoses of the aforementioned subjects' children appeared to be of lesser severity than the diagnoses of the remaining subjects' children. This study did not seek to determine levels of severity when comparing the medical disabilities of the subjects' children. Perhaps further research in this area could determine the

relationship between dental care barriers and the severity of the medical disability of the child.

Multiple subjects (55%) reported that their children had not been to a dentist or dental clinic. The sample responses were spread over a continuum from dental care not needed, to concern over the expense of dental care with lack of dental insurance coverage, to perceived and/or apparent lack of dentists willing and/or trained to treat children with special health concerns, and finally to the explanation that access to professional dental care had not been attempted. The median age of the children for which the subjects responded negatively on seeking professional dental care was 5.2 years. Two of the subjects specifically commented that they believed the first visit should be near the child's third birth date. This conclusion is in direct contrast to the recommendation by the AAPD that a child's initial visit to the dentist occur within six months of the eruption of the first primary teeth and no later than twelve months of age. This indicated that strong emphasis on the need for early dental care should be infused into parent education.

When subjects were asked to provide suggestions on improving dental care availability, results indicated that parents were somewhat reticent in their responses. Whether this indicated simply a lack of concern, the lack of ability to identify a cause and effect relationship, or concern over this researcher's reaction to criticisms of the dental community could not be determined in this study. When prompted, some recommendations were provided during the interview portion of the data collection. These suggestions generally involved the need for dentists trained to care for children

with special health concerns and resources to assist with the fees involved in dental care. While reserved in their responses, the subjects willingness to share the aforementioned thoughts should be considered important and utilized as a springboard to further parental proactivity toward improved dental care for their children. As suggested by Freire's empowering education theory, literature concludes that enhanced education can lead to greater society empowerment (Wallerstein & Bernstein, 1988). This increased involvement in community issues by the general public can be directed toward health promotion.

### Conclusion and Implications

Conclusions and the implications to dental health educators/professionals based on this study along with the corresponding research questions are delineated as follows:

1. What types of dental health information have been provided to parents/legal guardians for their children with special health concerns? Participants in this study indicated that they had acquired general dental care information with lesser numbers reporting having acquired information specifically related to dental care for children with disabilities. The implication of this conclusion is that dental health educators/professionals must either build from this information base or substitute with more accurate information to enhance efforts at improving oral health for children with special health concerns.

2. What are the barriers encountered by parents/legal guardians in providing dental care for their children with special health concerns? Participants in this study

identified multiple obstacles in providing dental care for their children with the majority expressing concerns related to difficulties in brushing. This fact is interesting when “ways to brush” was selected as the most common response to the question on acquired dental health information. Evidently knowing how to brush and actually accomplishing the task are not synonymous. The implication of this conclusion is that dental health educators/professionals must be ready to describe, demonstrate, and provided an opportunity for repeated supervised practice of alternatives in routine brushing strategies for those parents of children with special health concerns.

3. What are the barriers encountered by parents/legal guardians in accessing dental care for their children with special health concerns? Participants in this study denoted a diversity of issues related to accessing professional dental care including: (a) no attempt made due to lack of need or the child’s age, (b) expense of dental care with limitations in dental insurance coverage, and (c) few dentists willing and/or able to treat children with special health concerns, and (d) office structures not physically accommodating to wheel-chair bound children. The implication of this conclusion is that dental health educators/professionals must communicate more effectively the need for early dental intervention. The society of those dentists specifically trained to manage children with special health concerns (AAPD) must actively promote their recommendation for the child’s initial visit to correspond with his/her first birth date. This information should be shared with both the public and primary healthcare providers. Dental professionals should engage in legislative efforts to advance state and national

resources devoted to children's dental health, and, at the same time, seek support in the private sector. Dental educational institutions should broaden their curriculum to include courses designed to reduce dental student anxiety in caring for the medically disabled in conjunction with hands-on experiences. For the dental professionals already in practice, continuing education material could be designed to further advocate care of children with special health concerns.

4. What are potential promoters to improving dental care accessibility for children with special health concerns as identified by their parents/legal guardians? Participants in this study identified methods to improve the availability of dental care for their children in a limited fashion and, in several instances, prompting was necessary during the follow-up interview. Those stated involved the need for assistance in resources to cover dental fees and a greater availability of dentists trained to treat children with special health concerns. The implication of this conclusion is that dental health educators/professionals must raise public awareness of children's dental health needs through education. Individuals and communities may then realize that they, in fact, have some control in shaping the dental healthcare structure and may add their voice to those concerned over current system inadequacies. This empowerment may be beneficial in promoting an improvement in the dental health status of their children.

### Recommendations

Based on the findings of this study the following recommendations are suggested:

1. This study should be replicated using a larger sample to further examine

barriers to dental care for children with special health concerns. This could support the results of this study and provide additional data necessary in eliciting more generalizable conclusions.

2. The qualitative responses collected in this study should be adapted for use in a quantitative experimental research approach appropriate for larger sample sizes and tested for reliability. Information related to the correlation of barriers encountered and the severity of children's medical compromise should be added. Questions designed to determine perceptions of children's dental health needs could be included with a follow-up examination by a dental professional comparing actual dental treatment indications to the parents' perceptions of their children's dental disease. Data collected may allow for more advanced statistical analysis and correlations.

3. An additional study with a sample of pediatricians would be useful to determine awareness of AAPD recommendations on the timing of the child's first dental visit and if this information is conveyed to patients' families.

4. A study designed to review the efficacy and effectiveness of current dental health programs (e.g., fluoridated water supplies, school-based dental health education and oral screenings, fluoridated dentifrices, etc.) in reaching the population of children with special health concerns is also needed.

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## APPENDICES

## APPENDIX A

Approval from TWU Human Subjects Review Committee

TEXAS WOMAN'S  
UNIVERSITY  
DENTON/DALLAS/HOUSTON

HUMAN SUBJECTS  
REVIEW COMMITTEE  
P.O. Box 425619  
Denton, TX 76204-3619  
Phone: 817/898-3377  
Fax: 817/898-3416

December 3, 1996

Joni Hopps  
4208 Bretts Court  
Arlington, TX 76017

Dear Joni Hopps:

Social Security #: 466-13-9670

Your study entitled "Barriers to Dental Care for Children with Special Health Concerns" has been reviewed by a committee of the Human Subjects Review Committee and appears to meet our requirements in regard to protection of individuals' rights.

Be reminded that both the University and the Department of Health and Human Services (HHS) regulations typically require that signatures indicating informed consent be obtained from all human subjects in your study. These are to be filed with the Human Subjects Review Committee. Any exception to this requirement is noted below. Furthermore, according to HHS regulations, another review by the Committee is required if your project changes.

Special provisions pertaining to your study are noted below:

- ☒ The filing of signatures of subjects with the Human Subjects Review Committee is not required.
- ☒ Your study is exempt from further TWU Human Subjects Review.
- ☐ No special provisions apply.

Sincerely,



Chair  
Human Subjects Review Committee

cc: Graduate School  
Dr. Eva Doyle, Health Studies  
Dr. William Cissell, Health Studies

## APPENDIX B

### Agency Permission for Conducting Study

TEXAS WOMAN'S UNIVERSITY  
HEALTH STUDIES INSTRUCTION PROGRAM

AGENCY PERMISSION FOR CONDUCTING SURVEY

The The Texas Scottish Rite Hospital for Children

GRANTS TO

Joni R. Hopps

a student enrolled in the master's degree program in Health Studies Instruction at Texas Woman's University, the privilege of its facilities/data in order to study the following program:

Barriers to dental care for children with special health concerns.

The conditions mutually agreed upon are as follows:

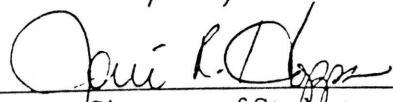
1. The agency (may) (~~may not~~) be identified in the final report.
2. The names of consultative or administrative personnel in the agency (may) (~~may not~~) be identified in the final report.
3. The agency (wants) (~~does not want~~) a conference with the student when the report is completed.
4. Other \_\_\_\_\_

DATE:

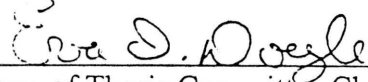
11/21/96



Signature of Agency



Signature of Student



Signature of Thesis Committee Chairman

## APPENDIX C

### Dental Health Questionnaire



**I UNDERSTAND THAT THE RETURN OF MY COMPLETED  
QUESTIONNAIRE CONSTITUTES MY INFORMED CONSENT TO ACT AS A  
SUBJECT IN THIS RESEARCH.**

Dental Health Questionnaire

Please complete the following:

Your Primary Language or Language Preference:

\_\_\_\_\_ English \_\_\_\_\_ Non-English

Your Child's Date of Birth:

\_\_\_\_\_  
(month/date/year)

Your Child's Primary Diagnosis (medical problem) as described by his/her doctor:

\_\_\_\_\_  
\_\_\_\_\_

INSTRUCTIONS: PLEASE ANSWER THE FOLLOWING QUESTIONS AS FULLY  
AS POSSIBLE (check all the responses that are applicable and give additional  
information that might be helpful)

1) What dental health information have you been given about your child? (check all that  
apply)

- \_\_\_\_\_ ways to brush the teeth
- \_\_\_\_\_ the need for fluoride
- \_\_\_\_\_ when the teeth should appear (erupt) in the mouth
- \_\_\_\_\_ age your child should see a dentist
- \_\_\_\_\_ how to manage oral habits (thumb sucking, teeth grinding, etc.)
- \_\_\_\_\_ age to limit or stop using the nursing bottle
- \_\_\_\_\_ care of the teeth if your child is fed through stomach or G-tube
- \_\_\_\_\_ how medications might affect the teeth or gums
- \_\_\_\_\_ none of the above
- \_\_\_\_\_ other--describe \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

2) The dental health information was provided by: (check all that apply)

- |  |   |
|--|---|
| <input type="checkbox"/> a doctor/physician            | <input type="checkbox"/> a friend or relative |
| <input type="checkbox"/> a nurse                       | <input type="checkbox"/> a teacher            |
| <input type="checkbox"/> newspaper or magazine article | <input type="checkbox"/> a dentist            |
| <input type="checkbox"/> television                    | <input type="checkbox"/> a dental hygienist   |
| <input type="checkbox"/> other--describe _____         |   |

3) What difficulties have you had in taking care of your child's teeth? (check all that apply)

- ☐ child does not (or is unable to) cooperate for brushing
- ☐ child does not like the toothpaste
- ☐ child swallows the toothpaste
- ☐ cleaning teeth/mouth takes too much time
- ☐ not enough time due to other care-taking tasks
- ☐ fear of hurting my child during brushing/cleaning mouth
- ☐ unsure how to brush/clean mouth properly
- ☐ other--describe \_\_\_\_\_

Describe the greatest difficulty you have had in taking care of your child's teeth.

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4) Has your child seen a dentist or been to a dental clinic in your community?

- ☐ yes--please go to part "a)" of this question
- ☐ no --please go to part "c)" of this question

a) If the answer is yes, do you/your child plan(s) to-- (check only one)

- ☐ return to the dentist for regular dental care
- ☐ return to the dentist for emergency care only
- ☐ not return to the dentist because dental treatment cost too much
- ☐ not return to the dentist because you/your child were (was) not happy with the care received
- ☐ not return to the dentist because they suggested your child see someone else
- ☐ other--describe \_\_\_\_\_

b) Was the dental visit a positive experience for you and your child?

\_\_\_\_\_ yes--please go to question "5)"

\_\_\_\_\_ no --please answer below

Describe any specific problems or negative experiences you/your child encountered during your child's dental visit. \_\_\_\_\_

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c) If you answered no to question "4)", why or what difficulties have you had in finding dental care for your child? (check all that apply)

\_\_\_\_\_ dental care not needed--child has no problems with his/her teeth

\_\_\_\_\_ dental care too expensive

\_\_\_\_\_ no dental insurance coverage for my child

\_\_\_\_\_ dentist contacted does not see children

\_\_\_\_\_ dentist contacted does not see children with special health concerns

\_\_\_\_\_ too busy to make an appointment

\_\_\_\_\_ not a specialized (pediatric) dentist in my community

\_\_\_\_\_ other--describe \_\_\_\_\_

\_\_\_\_\_

Describe the greatest difficulty you have had in finding dental care for your child. \_\_\_\_\_

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5) How could the availability of dental care for your child be improved? Name up to 3 ways. \_\_\_\_\_

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