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ADOLESCENTS' PERCEPTIONS OF THEIR ROLES IN DECISION-MAKING
IN THE ORAL CLEFT CLINIC

by

Rebecca Ann Hague

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Faculty of The Graduate College
in partial fulfillment of the
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Rebecca Ann Hague

ADOLESCENTS' PERCEPTIONS OF THEIR ROLES IN DECISION-MAKING IN THE ORAL CLEFT CLINIC

Rebecca Ann Hague, M.A.

Western Michigan University, 2007

Background: The literature suggests adolescents have the cognitive abilities equivalent to an adult for health related decisions. Adolescents should participate in treatment planning at a level equivalent to their cognitive abilities and the extent they desire. Little is known regarding adolescents' perceived and desired level of involvement in decision-making in an oral cleft clinic.

Purpose: To describe adolescents' perceptions of their roles and desired level of involvement in decision-making in an oral cleft clinic.

Methods: Four adolescents completed a questionnaire and participated in focus groups.

Results: Participants reported that they perceive they are involved in decision-making processes, are knowledgeable about their cleft, and believe they will be ready to make independent decisions by age 18. Participants advocated for increased autonomy, but some expressed a preference for parents to make decisions.

Conclusions: These preliminary findings suggest adolescents perceive they are involved in decision-making and will be ready to make decisions about their clefts when they turn 18. Most participants feel adolescents should play a major role, while others prefer that parents continue to make significant health related decisions. Findings are limited by a small sample size.

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CHAPTER I

INTRODUCTION

Cleft Lip and Palate

Cleft lip and/or palate are congenital structural anomalies. Oral clefts occur in approximately 1 out of 600 live births in the United States (American Cleft Palate and Craniofacial Association [ACPA], 2006) making oral clefts one of the most common birth defects and the most common congenital facial birth defect worldwide (Kummer, 2001a). The incidence of this condition varies by type, by gender, geographical location, and race. The etiology of the defect is unknown, but is attributed to the complex interaction of environmental and genetic factors (Schutte & Murray, 1999).

Treatment and Management Approaches

Cleft lip and/or palate are typically identified and repaired within the first year of life. However, individuals continue to encounter medical, dental, surgical, psychosocial, and communication difficulties throughout adolescence and adulthood (Kummer, 2001b). These defects are considered to be a chronic illness requiring supplementary healthcare services. A chronic illness not only affects an adolescent's growth and development, it also affects the development of his/her identity, social relationships, and educational and vocational engagement (Sawyer & Aroni, 2005). A variety of healthcare professionals evaluate and treat problems associated with cleft lip and/or palate using a team approach

(Kummer, 2001b). The team composition varies, but primarily involves a surgeon, orthodontist, speech-language pathologist, and psychologist (ACPA Team Standards Committee, 1996; Strauss & Broder, 1985).

The team approach offers coordinated and integrated care by allowing for a comprehensive and holistic evaluation of the child in fewer appointments and allows team members to share in treatment planning (Kummer, 2001b). This is beneficial to the client and is time and cost effective by combining office visits with several professionals at each visit (Kummer, 2001b; Strauss & Broder, 1985). Some disadvantages of a team approach relate to a hierarchical organization that may form between professional members, their perceived or ascribed status within a hierarchy, roles which are not clearly defined, and disagreement in the opinion of care among team members (Kummer, 2001b; Sharp, 1995). Halstead (1976) proposed that team care is more effective than “customary fragmented care” and suggested that team care may increase patient use of healthcare services.

A multidisciplinary team is a group of professionals who work independently in the evaluation and treatment of a particular patient within their individual areas of expertise. Healthcare professionals who are members of an interdisciplinary team work together to evaluate and to treat each patient (Kummer, 2001b). An interdisciplinary approach to team care is perceived as an effective way to provide comprehensive and coordinated treatment for patients with complex, chronic health conditions, such as cleft lip and/palate and craniofacial anomalies (Kummer, 2001b; Strauss & Broder, 1985). Limited literature exists on adolescent patient and parent’s perceived effectiveness of a

team approach to cleft lip and/palate management, including their role as members of the team.

Although team members are experts in their own fields, family members are considered to be the experts on the child. Until recently family members have held relatively passive, undefined roles on the interdisciplinary team (Nash, 1990). In part, public policies have tried to ensure family involvement in treatment planning in educational settings by creating Individualized Family Service Plans (IFSP) and Individual Education Plans (IEP). Although not mandated through legislation, patients and families should be active members of the cleft team and be included in the decision-making process. Including adolescents as members of the interdisciplinary team may facilitate the development of cognitive skills needed for more complex medical decision-making occasions (Harrison, 1997).

Adolescent Cognitive Development

Piaget described two stages of cognitive development that occur during late childhood and early adolescence: the concrete operational and formal operational stages (McLaughlin, 1998). The concrete operational stage generally occurs between 7 and 11 years of age and is characterized by the development of a young adolescents' ability to take another's perspective. According to Piaget, the formal operational stage usually begins at about 11 years of age and continues into adolescence and adulthood. The formal operational stage of cognitive development involves the development of intellectual capacity for reasoning, generalization, and abstract and hypothetical thinking. Like adult

cognitive processes, children and adolescents in the formal operational stage exhibit the capacity to apply reasoning beyond their immediate personal experiences.

Cognition continues to develop into adolescence and several cognitive theories suggest that this occurs in three stages: early, middle, and late adolescence (Inhelder & Piaget, 1958). Early in adolescence, between the ages of 10-13 years, adolescents are beginning to think concretely, yet are less systematic in their thinking and have limited ability to reflect on and combine past experiences with possible future experiences, when compared with their older peers (Inhelder & Piaget, 1958). In middle adolescence, between 14-17 years, adolescents begin to use more abstract thinking and hypothetical-deductive reasoning processes to think beyond the present to future possibilities. Finally, during late adolescences, between 18-21 years, adolescents have fully refined their abstract thinking abilities and are able to think about their present and future more realistically than their younger peers.

Previous research regarding the cognitive skills needed for decision-making in healthcare has found that 14 year olds' demonstrate cognitive and reasoning skills for decision-making similar to those of adults (Alderson, 2006; Berkowitz, 2005; Doig & Burgess, 2000; Fundudis, 2003; Weir & Peters, 1997). Inhelder and Piaget (1958) suggest that 14-15 year olds have developed propositional logic enabling them to begin to think about the future and commit to future possibilities. It is the skills and cognitive abilities that an adolescent develops before 18 that are important for a successful transition between pediatric and adult healthcare services.

Adolescent and Healthcare Professionals' Roles in Healthcare Transitions

Transition into adulthood is a dynamic process. The adolescent's environment combined with the cognitive skills s/he has developed and are currently developing, shape the transition from a dependent child to an independent adult (Aviles, Anderson, & Davil, 2006). When adolescents turn 18 years of age they are expected to be able to make medical decisions, yet adolescents do not instantly gain these decision-making and self-management skills (Sawyer & Aroni, 2005). As adolescents grow, they acquire skills that allow them to progress through stages of development (Aviles et al., 2006). The development of decision-making skills will be important as the adolescent makes the transition to being an autonomous adult.

Viner (1999) describes three key components for the transition to adult responsibility for healthcare decision-making: (1) age of transition; (2) envisioning the future; and (3) age of responsibility. The age of transition is briefly described as the selection of a target age of transition, typically between 17 and 18 years of age. Selecting a target age of transition is important in helping healthcare professionals, parents, and teens anticipate and prepare for the transition to adult care. In preparing for the transition, the primary caregiver and the physician are responsible for envisioning the future and anticipating opportunities for adolescents to participate in activities to promote their future independence. The age of responsibility, involves giving adolescents responsibility for activities and medical care that are proportional to their cognitive abilities. To encourage adolescents to take responsibility for healthcare, healthcare professionals should include them in the decision-making process. Professionals should review the reasoning behind a procedure and the expected progression of events with adolescents

(Sharp, 1995) as well as involve adolescents in the decision-making process (Viner, 1999).

A consensus statement for healthcare transitions of young adults with special needs suggests that it is important to plan the transition of responsibility for healthcare decisions, just as it is important to plan for adolescents' transitions into all other aspects of adult life (American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians-American Society of Internal Medicine, 2002).

Farrant and Watson (2004) noted both parents and adolescents perceived limited preparation and planning for the healthcare transition the adolescent would soon face. To date, there are no data describing whether adolescents with oral clefts perceive that they are included in decision-making in a manner that will help prepare them to make healthcare decisions independently once they reach the age of majority. Knowledge of perceived preparation for healthcare transitions will help professionals assist adolescents in developing the skills they will need to make a successful transition to an adult role in the healthcare system.

Consent and Assent in Medical Decision-Making

State laws vary regarding which individuals are able to consent to medical treatment and when they are able to make these decisions. In most cases, individuals are considered legally competent when s/he reaches adulthood, generally defined as the age of 18. Adults are assumed to be generally competent to make medical, financial, and personal decisions unless a court determines that the person lacks the cognitive abilities

to understand the decision, the available options, the likely outcomes of each choice, and is unable to demonstrate the ability to process treatment information (Appelbaum & Grisso, 1988; Bernat, 2001). Court determined incompetence is an “all or none” decision that carries wide sweeping implications and usually results in the court naming a legal guardian who is given authority to make decisions for that individual.

Rather than legal determination of competence, clinical settings apply the concept of decision-making capacity (DMC) (Appelbaum & Grisso, 1988). DMC refers to the degree to which an individual is able to understand treatment information and requires that the patient is able to: (1) demonstrate a choice; (2) understand of the outcomes of a choice; (3) provide rational reasoning; and (4) understand the risks and benefits of alternative treatment options (Appelbaum & Grisso, 1988; Weithorn & Campbell, 1982). DMC is determined in clinical settings, generally through a physician’s interactions with an individual and is evaluated specifically for a particular treatment planning occasion (Appelbaum & Grisso, 1988).

Informed consent is a patients’ agreement to a procedure, with an understanding of risks, benefits, and consequences of alternatives and is obtained before a treatment is initiated (Bernat, 2001). When giving informed consent it is required that the individual is provided with enough information to make an informed decision, and that information is presented in a non-coercive manner. Individuals 18 years or older who have decision-making capacity are able to give informed consent. In the medical setting individuals legally considered to be a minor are encouraged to participate in healthcare planning by giving assent in conjunction with their parent’s informed consent (American Academy of Pediatrics (AAP) Committee on Bioethics, 1995).

Assent is a minors' agreement to participate and is a concept often used in research (Sigman, Silber, English, & Epner, 1997). Healthcare providers should describe what an individual can expect from a treatment and evaluate a minor's understanding of a treatment using age appropriate language and terms (Bernat, 2001). When a healthcare provider seeks the assent of a minor, the healthcare provider demonstrates to the minor that his/her decision-making skills are respected and that the minor will be included in shared decision-making to the extent s/he is able to participate (Sigman et al., 1997).

Laws Associated with Medical Decision-Making

Laws vary by state regarding a minor's involvement in medical decision-making. In Michigan, minors are not able to give consent for most medical treatments (Status of Minors and Child Support Act, 1948). However, in the United States many states allow individuals under the age of 18 to consent to treatments associated with reproductive health, sexually transmitted diseases, drug abuse, mental health, and alcohol abuse (Bernat, 2001; Lyren & Silber, 2006).

It is not always necessary for the adolescent to reach adult status in order to provide consent for medical treatment (Lyren & Silber, 2006). In certain instances, a minor gains the right to consent to medical treatment. These include the cases of Emancipated Minors (Emancipated Minor Act, 1968) and Mature Minors (Illinois Mature Minor Act, 1989). Emancipation refers to "the termination of the parents' rights to custody of the minor, as well as control, services, and earnings of the minor" (Status of Minors and Child Support Act, 1948). Emancipation is typically granted to minors through legal proceedings (Miller & Reed, 2000). In Michigan there are four instances in

which a minor is considered eligible to be emancipated: (1) the minor is approaching the age of 18 years, (2) the minor is validly married, (3) the minor is in active duty with the armed forces and, (4) the minor needs non-surgical, emergency medical treatment when in custody of a law enforcement agency and a parent or guardian can not be reached (Emancipated Minor Act, 1968). In the last instance, emancipation is terminated upon completion of treatment or when the individual is released from custody. Emancipation grants the minor the same rights and responsibilities as an adult, except in cases such as alcohol consumption and voting in which a statutory age is defined (Miller & Reed, 2000).

In addition to emancipation statutes, some states have a Mature Minor statute, allowing individuals under the age of 18 specific rights to make decisions related to their healthcare. For example, the Illinois Mature Minor Act (1989) describes a mature minor as “an individual between the ages of 16 and 18 years of age who has demonstrated the ability to manage his/her own affairs and to live wholly or partially independently of his/her guardians or parents.” Within this act the minor, who is found by the courts to be a mature minor, is not fully emancipated and is only given the rights and responsibilities specifically defined by the courts, for example the ability to consent for healthcare treatment, such as surgery.

Medical Decision-Making in Adolescents

Shared decision-making occurs when the patient and the physician work together to create the best treatment plan for the individual (Bernat, 2001). In the past, adolescents were viewed as immature and less competent than adults to act in their own best interest

and for this reason were not routinely involved in decision-making (Silverman, 1983; Steinberg & Cauffman, 1996). Today, adolescents may not always be involved in the decision-making process, yet healthcare professionals and parents increasingly recognize the importance of acknowledging the adolescents' developing autonomy and fostering independence through inclusion in decision-making as s/he acquires the cognitive skills to participate in decision-making. Employing a family centered approach to treatment allows for the creation of a partnership between the healthcare professional, the parent, and the adolescent that will continue into adulthood (Harrison, Kenny, Sidarou & Rowell, 1997).

Adolescents with chronic illnesses who require repeated visits to healthcare professionals and numerous surgical procedures, gain experiences and maturity other adolescents may not (Harrison et al., 1997). Britto and colleagues (2004) summarize previous research suggesting that 12 to 18% of adolescents have one or more chronic illnesses, which require extensive healthcare services. Since adolescents with chronic illnesses have experienced a lifetime of medical care, they may possess a unique knowledge of their condition and related treatment procedures. For adolescents with oral clefts, frequent visits to healthcare professionals, experience with treatment and observations of the interactions between their parents and health professionals are likely to result in a familiarity with their medical condition and the kinds of considerations that go into treatment planning which is likely to facilitate their understanding of the decision-making process.

Team care should be provided in a manner that changes with the needs of adolescents and includes teens in decision-making at a level relative to their cognitive

abilities (AAP Committee on Bioethics, 1995; Silverman, 1983). Silverman (1983) describes ways to reform the manner in which team care is provided to children and adolescents in the oral cleft clinic. He suggests that the creation of a flexible team that changes with the needs of the child would in turn support an adolescent's development of autonomy. He also advocates for children's involvement in the decision-making process at an age and level proportional to the decision being made. Similarly the AAP Committee on Bioethics (1995) suggests that healthcare professionals should include adolescents in all healthcare related decisions at a level that coincides with their development, with adolescents gradually becoming the primary partner in shared healthcare decision-making. It is likely that including adolescents in healthcare decision-making would assist in the process of the transition to being an independent adult.

Adolescents state that inclusion in treatment planning as one of their preferences regarding healthcare. Recent research found that adolescents perceived the honesty of a healthcare provider as the most important quality of care preference when rated against healthcare quality statements including: "explaining things in terms I can understand," "listening to my point of view," and "having good medical knowledge" (Britto et al., 2004; Farrant & Watson, 2004). Attention to pain, knowledge of the patient's condition, confidentiality, and good listening skills were other common themes important to adolescents when talking about quality of care. In contrast, adults listed humaneness, competency or accuracy, and shared decision-making as their top three preferences when ranking statements regarding quality of care. Studies suggest that adolescents focus on healthcare provider characteristics rather than characteristics of the practice setting when ranking preferences for quality of care. In general, adolescents want to have honest

healthcare providers, to participate in care, to have their viewpoints heard, and to have things explained directly to them rather than their parents (Britto et al., 2004).

Evaluating the Decision-Making Capacity of Adolescents

The literature consistently states that adolescents as young as 14 demonstrate cognitive abilities similar to that of adults (Alderson, 2006; Berkowitz, 2005; Doig & Burgess, 2000; Fundudis, 2003). If adolescents are to be included in the decision-making process to the extent of their abilities, it is necessary for healthcare providers to evaluate an adolescent's decision-making ability each time a treatment plan is presented to them (Larcher, 2005). Difficulties arise when assessing the decision-making capabilities of adolescents (Tillet, 2005). As is the case for adults, there are no standard guidelines for the assessment of DMC in adolescents or instruments to measure when they are able to provide informed consent for medical treatment (Lyren & Silber, 2006; Tillet, 2006). Both formal and informal assessments of decision-making capacity have been used with adolescents.

Two formal assessments developed specifically for the evaluation of adolescent decision-making: the Adolescent Decision Making Inventory (ADI) (National Network for Child Care (NNCC), 1998); and the Adolescent Decision Making Questionnaire (ADMQ) (Tuinstra et al., 2000). The ADI is a semi-structured interview tool used to examine six elements in adolescent decision-making: (1) thinking patterns, (2) coping skills, (3) risk-taking behavior, (4) development of identity and personality, (5) goals and contingency planning, and (6) interpersonal processes are the six areas of focus of the interview questions (NNCC, 1998). The ADMQ uses the conflict model of decision-

making and self confidence to quantify patterns seen in adolescent decision-making (Tuinstra et al., 2000). The premise of this model is evident in the 5 subscales included in the 30 item self-report questionnaire. Subscales include: (1) self-confidence, (2) vigilance, (3) panic, (4) evasiveness, and (5) complacency and are used to describe an adolescent's decision-making style. These subscales are then used to place adolescents into one of two categories, either "adaptive" or "maladaptive" pattern of decision-making. Formal assessment measures such as those described are often time consuming and unsuitable for clinical settings as capacity is determined for each specific decision.

Scholars vary in their opinions regarding concepts or standards of capacity, yet most agree that an individual should possess an understanding of the information provided, and that the ability to communicate a choice is considered to be a universal sign of capacity (Alderson, 2006; Appelbaum & Grisso, 1988; Weithorn & Campbell, 1982). Other standards suggested by researchers include: contributing to and influencing the decision; demonstrating an appreciation of the associated outcomes; being the sole decision maker; and rationally manipulating information in order to reach a logical conclusion (Alderson, 2006; Appelbaum & Grisso, 1988).

Evaluating decision-making ability in each instance of shared decision-making is recommended since the nature of the decision changes with each occasion. Furthermore, decision-making capacity fluctuates with pain, mental state, and the context or environment (Larcher, 2005) as well as development. An adolescent's social and medical experiences may also have an impact on his/her capacity to make decisions, possibly increasing competence (Larcher, 2005; Sanci et al., 2005). Along with evaluating decision-making ability each time treatment planning occurs, it is also important for

healthcare providers to ensure adolescents understand the information being presented to them.

The adolescent's ability to understand the treatment plan and the condition itself is necessary in order to participate in shared decision-making and, will affect the assessment of decision-making capacity. Information about a treatment plan should be provided to adolescents in a way that is equivalent to their cognitive abilities and their understanding of the information should be evaluated (AAP Committee on Bioethics, 1995). The AAP Committee on Bioethics (1995) suggests that when receiving assent, the healthcare provider should: help adolescents develop an understanding of their condition that is developmentally appropriate; keep adolescents informed of what can be expected during testing and treatment; assess understanding of treatment plans; and ask for the adolescents' willingness to accept the treatment plan.

Alderson (2006) criticizes the research in adolescent decision-making processes and abilities because the focus is limited to competence and fails to consider processes of evaluating information in light of personal values and the weighing of alternatives. Mature decisions involve an interaction of both cognitive factors and psychosocial factors (Steinberg & Cauffman, 1996) and the ability to evaluate risks, benefits, consequences and the alternatives of treatment options. More research is needed to examine and evaluate the decision-making process of adolescents with oral clefts, their perceived roles, and desired level of involvement in decision-making.

Data Collection

There are multiple techniques that can be used to gather data regarding adolescents' perceptions of their experiences in the oral cleft clinic. These include interviews, surveys, and focus groups. Interviews allow the researchers to gather in-depth information related to individual opinions and experiences from individual participants through open-ended questions and follow-up questions (Greenbaum, 1998; Litosseliti, 2003; Morgan, 1997). The dynamics of an interview encourage the participant to provide additional information on a topic with little cuing from the researcher. Participants may also be more willing to disclose information about personal information such as drug and alcohol use when in a private interview situation. Although interviews may be a useful data collection technique, interviews can be time consuming with a large number of participants, follow-up questions may influence an participant to give a response that benefits the researcher, and there is no peer discussion of topics which may add to the richness of the data collected (Greenbaum, 1998).

Surveys let researchers collect a large amount of data quickly and can be more cost effective than either interviews or focus groups (Greenbaum, 1998; Litosseliti, 2003). Quantifiable responses are given to questions in a survey that can be generalized to a specific population, yet surveys do not allow for observation of participants and in-depth discussion of topics between participants. Surveys also often use rating scales which are less likely to capture the richness of information that can be gathered through open-ended questions (Litosseliti, 2003).

Focus groups allow examiners to hear how participants discuss a topic. Like interviews, focus groups let examiners ask open-ended questions and allow follow-up questions to clarify or enrich understanding of the participants' perspectives (Greenbaum, 1998; Litosseliti, 2003). When conducting focus groups, it is possible for follow up questions to reveal the interviewers bias or lead the participants to answer a question in a way that benefits the researchers. Since there are several people within the group, there may be false consensus if there is a participant with a strong personality who dominates the discussion (Litosseliti, 2003).

Historically focus groups have not been used frequently in social science research as examiners strive to gather quantitative data (Greenbaum, 1998; Litosseliti, 2003; Morgan; 1997). Recently, research has turned to focus groups as one primary way of gathering qualitative data in social science research. Qualitative data gathered from focus group could in turn be used as the basis for the creation of surveys.

Focus groups and a questionnaire were chosen for data collection for this study. The use of focus groups was selected due to its ability to capture the broadest opinions and views within this population. Using a focus group also allowed for follow-up questions leading from experiences shared by other group members to facilitate discussion to maximize the breadth of ideas. The questionnaire which was administered before the focus group discussion allowed a measure of individuals' individual perceptions, and may serve to offset the limitations associated with focus groups.

Purpose of Current Study

The purpose of this project is describe adolescents' perceptions of their current roles and desired level of involvement in decision-making in an oral cleft clinic. The qualitative data collected from this study will allow parents and healthcare professionals to consider adolescents' perceptions of experiences in an oral cleft clinic, particularly their perceived roles in decision-making. This information has the potential to aid parents and healthcare professionals with the debate of when and how adolescents should be integrated into clinical decision-making by ascertaining adolescents' ideas and opinions.

Research Questions

The goals of this study were to describe adolescents' perceptions about their role in decision-making and preferences for participation in decision-making within an interdisciplinary cleft team context. Specifically, this study was designed to address:

1. How knowledgeable do adolescents' perceive themselves to be about to their cleft condition?
2. Do adolescents perceive that they ask questions in an oral cleft clinic? If so, do they perceive that these questions are answered by healthcare professionals?
3. How do adolescents perceive their current role in decision-making about their treatment?
4. What are adolescents' preferences for level of involvement in decision-making?

Summary

While a team approach is most often used in evaluation and treatment of children and adolescents with oral clefts, little research has been conducted on the perceptions of adolescents within this group regarding the care they receive. Adolescents are particularly interesting because they are in a transition period from childhood to adulthood and are developing the skills needed to make medical decisions as adults. Adolescents vary in decision-making abilities and the level of input they are able to give to the decision-making process. The goals of this study were to describe adolescents' perceptions about their role in decision-making within an interdisciplinary cleft team and their preferences for participation in decision-making about treatment related to their oral cleft condition.

CHAPTER II

METHODS

Participants

The participants were four adolescents who had attended the Michigan State University/Kalamazoo Center for Medical Studies (MSU/KCMS) cleft clinic. Two participants were male and two were female. All participants were 15 years of age.

Participant Recruitment

Thirty-four adolescents were identified by MSU/KCMS cleft clinic and compiled into a mailing list. Adolescents who were between the ages of 13 years and 17 years 11 months, were able to hold a conversation in English, who had attended the MSU/KCMS cleft clinic within the last 4 years, and who had cleft lip and/or palate were sent a letter inviting them to contact the investigators in order to learn more about the study. Those who expressed interest were invited to participate in a small focus group held at the College of Health and Human Services on Western Michigan University's campus. Of the 34 adolescents on the mailing list, there were 21 non-responses, 3 letters were undeliverable, 4 were not interested in participating, and 6 expressed an interest in the study. Of the 6 possible participants one did not meet the study criteria as s/he was over the age of 18 years and one did not return scheduling phone calls. A subsequent mailing was completed and no additional participants were identified.

Protocol

The protocol included the collection of demographic data, a scaled questionnaire (see Appendix A), and responses to open-ended questions presented in a focus group format (see Appendix B). The protocol and consent documents were reviewed and approved by the Human Subjects Institutional Review Board (HSIRB) at Western Michigan University (see Appendix C).

A parent gave informed consent and the adolescent gave assent before data collection began. Adolescents were also asked to sign a confidentiality agreement stating they would not use other participants' names when discussing topics or opinions from the focus group. Each participant was asked to complete a demographic information form and answer an eight item scaled questionnaire about experiences and preferences for care related to his/her cleft.

A script was created to guide the focus group sessions, to ensure all research questions were addressed, and to provide consistency between focus groups (see Appendix B). Focus groups were led by the researcher and a facilitator. Throughout the session, the groups' main ideas were tracked by participants in brainstorming tasks and by the researcher on flip charts. Focus group sessions were video and audiotaped and later transcribed into Microsoft Word.

Analyses

The Word documents were reviewed for accuracy by a listener naïve to the goals of the study. The completed transcriptions were transferred into N6 (QSR, 2000), a computer software program which allows for analysis of themes in qualitative data.

Analyses of Open Ended Questions

Responses to open ended questions were transferred into N6. Once documents were uploaded top level “tree nodes” were used to organize and store the documents by question. Nodes are a tool within N6 to assist in the organization of ideas or themes and are of three types: (1) top level tree nodes, (2) tree nodes, and (3) free nodes. Top level tree nodes are used to organize main documents and additional tree nodes created from analyses of data. Text searches, new documents, or current documents can be used to create tree nodes; these generate an organizational structure for ideas and themes within the main document. Free nodes are those nodes created from searched themes or new documents that have not been organized under or within tree nodes. Organizing the data by nodes allows the researcher to expand certain ideas or nodes, as well as collapse these ideas or nodes with other nodes without losing the initial coding and organization.

Search terms are used to find themes or ideas within nodes. Search terms can be selected based upon the researcher’s hypotheses of what maybe expect or by reviewing the data. Once responses containing a theme are identified using a text search, these responses can be coded to or combined with an existing or new node. There are several ways which documents can be coded; a researcher can use a text search or browse documents for search terms. Responses that contain a search term can be coded or saved to a new free node, which can then be attached to or merged with an existing tree node, or used to create a new tree node. The researcher can also browse documents and manually select text to be included in a node. For example, a top level tree node was created to store all participants’ response to the question “What role do you think teens should play in decision-making?” This node was then searched, using a text search, for possible

themes. For example, the search terms “whole team” and “I want to” were used and identified two major themes that were grouped into individual tree nodes: (1) shared decision-making and (2) decision-making autonomy. This process was completed for each question asked during the focus group question.

Initial search terms were selected based on anticipated themes and a review of the participants’ responses. These search terms were applied to each question and used to organize themes in response to each research question. Results of the searches were reviewed to ensure all participants’ ideas and opinions were accounted for. Any non-coded responses were examined and new search terms were created. Once all participants’ responses were coded, each response was checked to ensure the content and sense of each comment truly fit with the themes identified. These themes were used to describe how the adolescents talk about experiences and preferences related to decision-making in the oral cleft clinic.

Analyses of Scaled Data

Scaled items from the questionnaire were entered using a scale of -2 (strongly disagree) to 2 (strongly agree) with 0 being neutral. The mean, median, and standard deviation were calculated for the scale-scored items relating to adolescents’ perceptions of their experiences in the oral cleft clinic using Excel 2003. Items included questions regarding knowledge of cleft, asking and getting answers to questions, as well as current and future decision-making.

CHAPTER III

RESULTS

Adolescents' Perceived Knowledge Regarding Their Cleft

Participants were asked to scale items related to their perception of involvement in the oral cleft clinic (see Appendix A). In response to the statement "I am knowledgeable about my cleft" participants chose either strongly agree or neutral ($\bar{x}=1.5$, s.d. =1.32). Scaled items are summarized in Table 1.

Adolescents' Perceptions of Their Question Asking Behaviors

Participants strongly agreed or were neutral in response to the statement "I ask questions about my cleft" ($\bar{x}=0.34$, s.d. =1.41). Written responses to what participants thought during a previous treatment planning session generated the theme: questioning reasoning behind the procedure, for example "why do I have to have this surgery?" Attempting to gain information was a theme noted in participants' written responses when asked what they said during a previous treatment planning session, for example "How long is it going to take?" (see Table 2). Responses to the statement "I get answers to my questions" were strongly agree or no response ($\bar{x}=2.0$, s.d. =0.0).

Adolescents' Perceived Current Role in Decision-Making

Participants either agreed or strongly agreed with the statement “I will be ready to make decisions about my general health when I turn 18” (\bar{x} = 1.25, s.d. = 1.66).

Responses to “I will be ready to make decisions about my cleft when I turn 18” ranged from agree to strongly agree and yielded a mean of 1.67 and a standard deviation of 0.82.

Participants agreed or strongly agreed with the statement “I already make decisions about my general health” (\bar{x} = 1.5, s.d. = 1.44). In response to “I already make decisions about my cleft” participants either strongly agree or agree (\bar{x} = 1.25, s.d. = 1.66).

When asked how a previous treatment decision was made two general themes arose. Participants noted a triadic shared decision-making model was most often used and included themselves, a parent, and the healthcare professional. For example one participant stated “there was me, my mom, and the doctor and we all kind of talked about what was best.” Shared decision-making between a healthcare professional and parent only was another theme raised by adolescents during the focus groups. Themes and participant responses are presented in Table 2.

Each participant was asked to write what they thought, how they felt and what they said when a treatment plan was discussed. Participants' responses to what they were thinking centered on two themes: (1) acknowledging the benefit of the procedure and (2) questioning reasoning behind the procedure. For example a participant wrote “I wanted the hole closed because when I drank it made a whistling noise” acknowledging the benefit of the procedure, where as another wrote “why do I have to have this surgery?” questioning the reasoning behind the procedure. Written responses are summarized in Table 3.

Uncertainty and general benefit were themes identified from participants' written responses to how they felt during a previous treatment planning session. "I really wanted it closed because sometimes it gets embarrassing when stuff came out of my nose" is an example of a general benefit and "I don't remember, slightly scared maybe" of uncertainty.

Participants' written response to what they said during the treatment planning session generated three themes: (1) making treatment suggestions, for example "Please, do the procedure so 'they' will stop picking on me," (2) attempting to gain information; "How long is it going to take, when is it going to be done," and (3) feeling treatment was unnecessary; "I argued against having it because I felt I didn't need it."

When the participants completed the activity on paper they were given an opportunity to discuss any perceived differences between what they thought, how they felt and what they said. Most participants did not talk about differences they had identified in writing, but one participant acknowledged "I didn't say what I thought."

Adolescents' Preferences for Level of Involvement in Decision-Making

When asked what role teens should play in decision-making/who should make the decision, participants' responses generated two themes: (1) decision-making autonomy, for example "I want to; if I want to say yes or no to what's going to happen" and (2) shared decision-making with a parent, for example "I like my mom to help me decide about that, like if I should have it done." Preference for desired level of involvement themes are summarized in Table 4.

Adolescents' Preferences for Conduct of an Oral Cleft Clinic

Other suggestions for the conduct of the cleft clinic included being asked biographical questions only once during their day attendance at the clinic; and, having notes placed outside each room stating whether or not the adolescent has the choice of seeing that professional without a parent. Participant responses are summarized in Table 5.

CHAPTER IV

DISCUSSION

The primary purpose of this study was to describe adolescents' perceptions of their current and desired roles in decision-making in an oral cleft treatment clinic. Four adolescents, who had attended the MSU/KCMS oral cleft clinic, participated in one of two focus groups. Completed paper and pencil focus groups provided preliminary data to describe how adolescents talk about experiences in decision-making and their desired roles in treatment planning and decisions.

Adolescents' Perceived Knowledge Regarding Their Cleft

Based on individually completed scaled attitude statement responses, three of four participants strongly agreed they were knowledgeable about their cleft and one was neutral about the statement. It appears this sample of teens generally perceive that they are knowledgeable about their cleft condition. Knowledge of condition could be another factor that affects adolescents' decision-making ability and their transition to being an autonomous adult.

Adolescents' Perceptions of Their Question Asking Behaviors

Participants responses regarding whether or not they ask questions related to their cleft suggest that they perceive that they do not ask questions. However, participants

perceived that when they ask questions they get answers to these questions. These scaled response data may appear to contradict each other; suggesting that although adolescents may not ask all of their questions during treatment planning sessions, during the team visit the questions they have do get answered. This may occur because their parents ask additional questions or because the healthcare professional anticipate and address concerns without a question being asked. These responses may also reflect that although these teens may feel that they do not ask many questions, when they do ask, their questions have been answered.

Themes generated from written responses to what participants thought and said during a previous treatment planning session seem to support participants' response to scaled statements suggesting that they do not ask all of their questions. Written responses suggest that adolescents feel that they have questions, but do not always ask those questions during treatment planning sessions. When asked to describe their reactions during treatment planning only one participant indicated attempts to gain information by asking questions. Taken together these data suggest that adolescents may have questions about treatments, yet may not ask all of their questions during treatment planning sessions. Future research is warranted to examine why adolescents do not ask questions, if they have them, and how oral cleft clinics can be structured to encourage adolescents to ask questions during treatment planning.

Adolescents' Perceived Current Roles in Decision-Making

The scaled data reflect that participants believe that they have been involved in shared medical decision-making and that this involvement has begun to prepare them for

the transition from pediatric services to adult healthcare services. Most participants feel they were involved in shared decision-making during a previous session, while one reported that the decision was made between a parent and healthcare professional. Themes generated from participants' written responses to what they said during a previous treatment planning session suggested that most participants attempted to involve themselves in treatment planning by requesting to have procedures completed.

Adolescent involvement in decision-making may differ depending on family dynamics and values, as well as between healthcare professionals. When asked how decisions had been made regarding a previous treatment, two themes emerged: (1) shared decision-making triad between teen, doctor, and parent and (2) shared decision-making between a parent and the healthcare professional. It is encouraging to note most participants felt they were involved in decision making as previous research stresses the importance of involving adolescents in decision-making (Harrison, 1997; Silverman, 1983; Viner, 1999).

Adolescents' Preferences for Level of Involvement in Decision-Making

Most participants feel they were involved in the decision-making process in development of the most recent treatment plan. Along with feeling included in the decision-making process, most participants reported they would like to have a major role in final decisions about treatment such as surgery. Themes generated by participants regarding roles in decision-making centered on: (1) decision-making autonomy and (2) shared decision-making. These findings are supported by the AAP guidelines (1995) that recommend that adolescents participate in decision-making at a level that is equal to their

cognitive abilities, with adolescents gradually taking a primary role in shared decision-making.

The themes raised by the adolescents in this study demonstrate their desire to be involved in decision-making; what differs is the level at which they want to participate. One participant reported the desire for help from a parent when making decisions in an oral cleft clinic while other participants advocate for teens to have increased decision-making autonomy. This finding is consistent with previous literature suggesting that the ability and desire to participate in decision-making vary between individuals (Larcher, 2005; Sanci et al., 2005). Variation in desired level of participation in shared decision-making may reflect individual differences among adolescents; the age and maturity level of the adolescent, or may vary depending on the treatment being discussed.

Participants' responses to the scaled attitude questionnaire and open-end focus group questions suggest they perceive themselves as prepared to make the transition from pediatric to adult services. Most participants believe they are knowledgeable about their cleft, feel involved in decision-making and feel they will be prepared to make decisions regarding general health maintenance and their cleft when they reach 18 years of age. This suggests a relationship between involvement in decision-making before the age of 18 and perception of ability and preparedness in decisions-making once adolescents turn 18 years old. Previous research suggests facilitating the development of decision-making skills through inclusion in shared decision-making aids in the preparation for transition from pediatric to adult healthcare services (Aviles et al., 2006; Harrison, 1997).

It seems that for the adolescents included in this study, their previous experiences and involvement in decision-making has fostered the onset of the transition to

independent decision-making. This finding is encouraging because a previous study of adolescent and parent perceptions of healthcare noted both parents and adolescents felt there was little planning for healthcare transitions (Farrant & Watson, 2004). Themes raised by participants during the focus group suggest they perceive that they have the foundations for a successful transition to adult services.

Adolescents' Preferences for Conduct of an Oral Cleft Clinic

Themes generated when adolescents were asked if there were any other topics they would like to discuss centered on the conduct of an oral cleft clinic. Some adolescents expressed a desire to have healthcare professionals note if an adolescent has the option of seeing that healthcare professional alone. Participants' desire to have more responsibility regarding management of their cleft is suggest by their preferences for conduct in an oral cleft clinic. Findings from this study suggesting that adolescents would like to play a major role in treatment planning are consistent with previous research stating adolescents' preferences for quality of care including: the desire to be involved in treatment planning, and to have treatments explained directly to them rather than their parents (Britto et al., 2004)

Limitations

The small number of participants and small number of focus groups limits the generalizability of these data. A larger number of participants and larger groups of 5 to 8 participants may have resulted in additional themes and varying points of view. Using focus groups comprised of male and female participants may also have affected the

adolescents comfort level and answers they provided. This study was completed with participants from a single cleft clinic and who have interacted with a number of the same professionals in the community. Future research will need to be broadened to include adolescents from other oral cleft clinics.

Future Research

Future studies with larger focus groups should encompass a wider age span and other oral cleft clinics will provide additional insight into the conceptual ability of adolescents. Comparison of adolescents' perceptions from different cleft clinics, as well as cleft clinics that may share some healthcare professionals may be a direction for future research, as it may provide insight regarding successful methods used by healthcare providers in preparing adolescents for the transition into adulthood. Future studies should examine adolescents' perception of readiness for transition and the practices of the cleft palate clinic they attend. One approach to evaluating adolescents' perceptions of readiness to make decisions would be to compare adolescents' views with the perceptions of their parents and health care providers within the oral cleft clinic. Further research should examine the process adolescents use when weighing treatment options, asking questions, and providing rationale for treatment choices in an oral cleft clinic.

CHAPTER V

CONCLUSION

Adolescents born with chronic illnesses such as cleft lip and/or palate have gained experience dealing with a variety of medical issues and familiarity with shared decision-making in a healthcare environment. This study provides preliminary insight into adolescents' perceptions and preferences related to experiences in the oral cleft clinic, particularly their role in decision-making. These findings suggest most adolescents feel that they are involved in medical decision-making and will be ready to make decisions related to additional treatment for their clefts when they turn 18 years of age. Participants gave mixed responses about the role adolescents should have in decision-making with some suggesting teens should play a major role in treatment planning and others wanting a parent to serve as the primary decision maker. These findings may also be used as a basis for future research involving adolescents' preferences and perceptions of team care in other contexts, across broader age spans, and allow further exploration of individual preferences that may vary by gender and culture. Continued study of adolescents' perceptions and preferences for involvement in healthcare decisions has broader implications for understanding the transition from childhood to the autonomy ascribed to adults in all areas of healthcare.

Table 1.

Scaled Attitude Questionnaire Responses

Attitude Statement	Mean	Median	Standard Deviation
1. I am knowledgeable about my cleft	1.50	2.0	1.32
2. I ask questions about my cleft	0.34	0.0	1.41
3. I get answers to my questions	2.00	2.0	0.0
4. I will be ready to make decisions about my general health when I turn 18.	1.25	1.0	1.66
5. I will be ready to make decisions about my cleft when I turn 18.	1.67	2.0	0.82
6. I already make decisions about my general health.	1.50	1.5	1.44
7. I already make decisions about my cleft.	1.25	1.0	1.66

Note: response scale; Strongly agree (2), agree (1), neutral (0), disagree (-1), and strongly disagree (-2).

Table 2.

Perceptions of Current Role in Decision-Making

Topic	Examples
Shared Decision-Making	
Triad	<ul style="list-style-type: none"> • There was me, my mom and the doctor and we all kind of talked about what was best and explained why it would be better for it to be done now. • Me, and Dr. Joe^a a lot but my mom was also in with him I would say and Dr. Miller^a and all the rest of the team, cause they kind of need to make decisions together. • It was like the same; we all sat down
Dyad	<ul style="list-style-type: none"> • My mom and I don't know who was subbing for Smith^a. He's the oral surgeon^b.

^a Names were changed to maintain confidentiality.

^b Statement is in response to the focus group question "Now think back again to the last time there was a decision made about a treatment, whether it was surgery or something else; how was the decision made?"

Table 3.

Participants' Written Perceptions of What They Thought, Felt, and Said During Decision-Making and Comments Related to This Task Elicited Through Discussion

Topic	Participant Responses
<hr/> Written responses to "What I thought" <hr/>	
Acknowledge Benefit	<ul style="list-style-type: none"> • I wanted the hole closed because when I drank it made a whistling noise. • Maybe if I get surgery and look better I would fit in.
Questioning Reasoning	<ul style="list-style-type: none"> • Why do I have to have this surgery? • Why is my jaw getting broken?
<hr/> Written responses to "What I felt" <hr/>	
Uncertainty	<ul style="list-style-type: none"> • I don't remember slightly scared maybe.
General Benefit	<ul style="list-style-type: none"> • I'm getting it done early • I hated them for not liking me the way I was and just wanted to fit in. • I really wanted it closed because some times it gets embarrassing when stuff came out my nose.

Table 3—Continued

<p>Written responses to “What I said”</p> <hr/>	
Gain Information	<ul style="list-style-type: none"> • How long is it going to take? When is it going to be done?
Treatment Suggestion	<ul style="list-style-type: none"> • I told the doctor about the noise and that I wanted the hole closed. • Please do the procedure so “they” will stop picking on me.
Unnecessary Treatment	<ul style="list-style-type: none"> • I don’t remember, oh yeah, I argued against having it because I felt I didn’t need it.
<p>Discussion response to “Is there a Difference?”</p> <hr/>	
Same	<ul style="list-style-type: none"> • They are the same • Well, What I was thinking and what I said really it was the same. • What I thought and felt and said were actually pretty much the same.
Different	<ul style="list-style-type: none"> • I didn’t say what I thought

Table 4.

Preferences for Desired Level of Involvement in Decision-Making

Themes	Participant Responses
Shared Decision-Making	<ul style="list-style-type: none"> I like my mom to help me decide about that, like if I should have it done.
Decision-making Autonomy	<ul style="list-style-type: none"> What I would like in my treatment would be for me, if it comes down to it, if I want to say yes or no to what's going to happen. They should have most of the say in that, in the decision. Yeah, have most of the say; express thoughts and feelings, but have doctors say when.

Table 5.

Preferences for Conduct of Oral Cleft Clinics

Themes	Participant Responses
Ask biographical questions once	<ul style="list-style-type: none"> • They ask you the same questions in all the different rooms so I think that after you get there they should be like “Okay, what’s your name, what school do you go to?” just ask you that after you get in, and then do what you’re specialized in.
Professionals they can see alone	<ul style="list-style-type: none"> • Some doctors put a note on the door, the patient does not want their mom or dad there they can choose not to have them there.
See all professionals at once	<ul style="list-style-type: none"> • Instead of having a check-sheet and going to every doctor separately, I think maybe they should get like into a group meeting, yeah pretty much like this and say what everyone thinks, and they all make decisions that are kind of like a chain reaction.

Appendix A

Demographics and Attitudes Questionnaire

Demographics and Attitude Questionnaire

Name: _____

Age (in years): _____ years Gender (please check one): Female ☐ Male ☐

Approximately when was your most recent visit to the Oral Cleft (or Cleft Palate) Clinic?

(month, year)

Who usually goes with you to the cleft clinic? (i.e. Mom, Dad, Aunt, etc) _____

What school do you attend? _____

Please check one box for each of the following questions:

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
I am knowledgeable about my cleft	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I ask questions when I visit the oral cleft clinic	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I get answers to my questions in the oral cleft clinic	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I will be ready to make decisions about my general health when I turn 18	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I will be ready to make decisions related to my cleft when I turn 18	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I already make decisions about my general health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I already decisions related to my cleft	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendix B

Focus Group Script

Focus Group Script

Thank you for coming here today/tonight. We have asked all of you to come so we can hear what you have to say about some of your experiences in the cleft clinic.

We would like you to understand that we aren't looking for a specific answer, since there are lots of different ways to think about healthcare for teens. It is alright if you disagree with each other. We want to be able to hear everyone's opinion and ideas. We are going to try and give everyone an opportunity to give their opinion, however if you don't want to answer a question you don't have too. We are going to ask you to use first names only, even if you already know someone in the group, and we ask that you try not to use names if you decide to talk with others about this discussion.

I am going to ask some questions and making sure each of you has a chance to answer, and (Bethany/Rebecca) is going to write things down and keep us on time. We may also have some of you come up and write down some of the ideas that the group comes up with on our white board/flip chart.

If you have any questions or concerns at any time please stop and ask. Any questions?

Does anyone need a drink or snack before we start? Please feel free to get one at any time.

Warm-up Question

I'd like each of you to tell us (1) your first name, (2) where were you born, (3) and tell one thing you like to do in your free time.

I'll go first. My name is _____, I was born in _____, and I like to _____.

Thanks everyone-now we would like to hear a little bit about your experiences when you visit the Oral Cleft Clinic. I want you to think back about times when you have come to the cleft clinic. How many of you go to the clinic with a parent or another adult? Please raise your hand if you usually have a parent with you.

Introductory Question

- (1) Please use the paper in front of you to list some advantages of having a parent with you at the cleft clinic. (Pause 2-3 minutes)
- (2) Using that same paper, please list some disadvantages of having a parent with you. (Pause 2-3 minutes).

Okay, I'd like talk about the things everyone thought about. Remember, we are interested in hearing everyone's ideas.

- (1) Let's make a list of the advantages and disadvantages of having a parent with you. (use white board or flip chart, just list-no discussion)
- (2) Of everything up here, what do you think is the most important advantage?
- (3) What is the most important disadvantage?

Transition & Content Questions

- (1) Think back to your last visit to the cleft clinic. Would you have talked to the doctors differently if you were by yourself?
- (2) Are there certain people of the oral cleft team that you would prefer to see by yourself?
- (3) Think back to the last time you discussed a treatment, like a surgery, related to your cleft. How was the decision made about whether you should have the treatment?
- (4) Using the picture on this sheet of paper (hold up paper), write down or draw:
 - a. What you *said* about the suggested treatment.
 - b. What you *thought* about the suggested treatment.
 - c. What you *felt* about the suggested treatment.

(Pause 4-5 minutes)

Are there any differences between what you said, thought or how you felt about the decision regarding the treatment?

Ending Questions

We've talked about a lot of things today, such as (give a number of examples).

I'd now like everyone to break into smaller groups of 2-3, to think about the ideas we've talked about and develop some recommendations about:

- (1) How you think teens should be seen in the Oral Cleft Clinic.
- (2) What role should teens play in decisions about treatments, like surgery.

Please be as specific with the information as you can. For example, if you think teens should be seen alone, at what age should this begin? (Give teams marker and flip chart, pause 8-10 minutes)

Let's look at what everyone came up with.

Final Question

(10 minutes prior to end of session)

Thank you very much for your thoughtful ideas and suggestions. This has been a great discussion, but before we finish up here, I'd like to make sure we covered everything you think is important.

Is there anything we haven't talked about that you would like to discuss?

Appendix C

Human Subjects Institutional Review Board Approvals

WESTERN MICHIGAN UNIVERSITY



Human Subjects Institutional Review Board

Date: October 31, 2006

To: Helen Sharp, Principal Investigator
Bethany Barris, Student Investigator for thesis
Rebecca Hague, Student Investigator for thesis

From: Amy Naugle, Ph.D., Chair

A handwritten signature in black ink, appearing to read "Amy Naugle", written over the printed name.

Re: HSIRB Project Number: 06-10-10

This letter will serve as confirmation that your research project entitled "Perceptions of Adolescents in the Oral Cleft Clinic" has been **approved** under the **expedited** category of review by the Human Subjects Institutional Review Board. The conditions and duration of this approval are specified in the Policies of Western Michigan University. You may now begin to implement the research as described in the application.

Please note that you may **only** conduct this research exactly in the form it was approved. You must seek specific board approval for any changes in this project. You must also seek reapproval if the project extends beyond the termination date noted below. In addition if there are any unanticipated adverse reactions or unanticipated events associated with the conduct of this research, you should immediately suspend the project and contact the Chair of the HSIRB for consultation.

The Board wishes you success in the pursuit of your research goals.

Approval Termination: October 31, 2007

Walwood Hall, Kalamazoo, MI 49008-5456
PHONE: (269) 387-8293 FAX: (269) 387-8276

WESTERN MICHIGAN UNIVERSITY

H. S. I. R. B.

Approved for use for one year from this date:

OCT 31 2006

Amy Naege
HSIRB Chair



WESTERN MICHIGAN UNIVERSITY

Department of Speech Pathology and Audiology
College of Health and Human Services
November 8, 2006

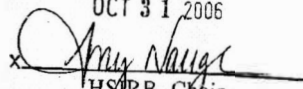
To Whom It May Concern,

This letter is to invite your teenaged child to participate in a research project entitled "Perceptions of Adolescents in the Oral Cleft Clinic." Team clinics are the most common approach to coordinating treatment for individuals who were born with a cleft lip and/or palate. The purpose of this project is to learn about adolescents' experience in the oral cleft clinic.

Your teenager was selected as a possible participant in this project from a list of individuals who have been seen by the Oral Cleft Clinic at the Kalamazoo Center for Medical Studies (KCMS) run by the Michigan State University (MSU). If your teenager chooses to participate they will meet with a small group of other adolescents to talk their experiences and help to make suggestions for improving team care for teenagers. The group discussions will be held at Western Michigan University's College of Health and Human Services (next door to the KCMS/MSU Clinic). Your teenager will spend between 1 and 2 hours at WMU. Upon completion of the group discussion, your teenager will be given a twenty-dollar gift certificate as a token of our appreciation for participating. The sessions will be video and/or audio taped and later typed into a computer file. This information will be kept as on a computer and as hard copies in a filing cabinet in a locked research lab with in the College of Health and Human Services. Participants in the focus groups will be identified by an identification number in order to keep their identity confidential.

The purpose of this study is to help us learn more about how to improve clinical care for teenagers. We do not expect that your teenager will benefit from participating in this study, but we hope that what we learn will help other children and professionals in the future. We do not know of any risks to participating in this study, but it is possible that your teenager will not want to answer some questions. We will explain that your child may choose not to answer or participate in the discussion and is free to leave at any time. It is possible that other people in the study will learn your child's name. To minimize this possibility, each participant will be given a choice to use an alias and we will use a first-name only policy during the discussion. Each participant will be asked to keep the comments of others confidential after the discussion is complete. Your teenager will be free to decide to participate or not, even if you say yes.

WESTERN MICHIGAN UNIVERSITY
H. S. I. R. B.
Approved for use for one year from this date:

OCT 31 2006

HSIRB Chair

This study is being conducted by Bethany Barrus and Rebecca Hague, graduate students in the Department of Speech Pathology and Audiology at Western Michigan University. This project is supervised by Helen Sharp, Ph.D. Assistant Professor at WMU.

If your teenager would like to participate please complete and return the enclosed form or contact the investigators at 269.387.7060 for more information. We will ask your teenager (or you the parent) some questions over the phone to make sure your teenager will be able to participate. We will need to obtain your permission as well as agreement from your teen. If you do not wish to participate, please return the form or call (269) 387-7060 and let us know so we don't send any additional reminders to you. If you have any questions about this letter or the project you may contact Helen Sharp at (269) 387-8024 or the Human Subjects Institutional Review Board of Western Michigan University (269) 387-8293 or the Vice President for Research at Western Michigan University (269) 387-8298.

This study has been reviewed and approved by the Human Subjects Institutional Review Board of Western Michigan University. This letter has been approved for use for one year by the Institutional Review board as indicated by the stamped date and signature of the board chair in the upper right corner. You should not respond to this letter if the stamped date is more than one year old.

Sincerely,

Bethany Barrus, B.A.
Graduate Student

Rebecca Hague, B.S.
Graduate Student

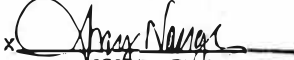
Helen M. Sharp, Ph.D.
Assistant Professor

Assent for Individuals 14 to 17

OCT 31 2006

**Department of Speech Pathology and Audiology
Western Michigan University**

Investigators: Helen Sharp, Rebecca Hague, Bethany Barrus

x 
HSIRB Chair

You have been invited to participate in a research project entitled "Perceptions of Adolescents in the Oral Cleft Clinic." This research is intended to help us learn more about how to improve clinical care for teenagers. This research is a thesis project for two graduate students, Rebecca Hague and Bethany Barrus.

If you agree to participate you will attend a group discussion with 4 or 5 other adolescents who have been seen in the Oral Cleft Clinic. The discussion will last for about an hour and a half. The group will be lead by Rebecca Hague or Bethany Barrus and will meet in the College of Health and Human Services building at Western Michigan University.

If you decide to participate we will give you a one-page form to fill out before the group meets. You can skip any questions on this form.

The group discussion will focus on teens' observations and suggestions for visits to the Oral Cleft Clinic. We are interested in learning about your ideas and what you think about how the Oral Cleft Clinic works for teens. You are free to choose not to answer some or any questions in the group discussion. You are free to leave the group at any time.

We do not know of any problems or risks to you from participating in this project. It is possible that you will get bored or may not want to answer some questions and that is fine. It is possible that other teens in the study will learn your first name. You can choose to use another name during the discussion and we will use only first names in order to protect your health information. When we write down what people say we use identification numbers and not names, so what you say will not be tied to your name. All forms and data related to this project will be kept in a locked filing cabinet in a research laboratory in the College of Health and Human Services Building.

We do not expect you to benefit from participating in this study. The reason for doing the study is to help us understand teenagers' views. We hope that what we learn will help adolescents, parents, and professionals in the future.

All of the information collected from you will be confidential. All data forms will use identification numbers and not names, except this form and the form you sent us with your name, age, and phone number for scheduling the group discussion. Once all the data are collected we will destroy the contact information form. We will keep the other information from the discussion for at least three years in a locked file in the principal investigator's laboratory.

You may choose to stop participating in this study at any time without any effect on medical services to yourself. If you have any questions or concerns about this study, you may contact Rebecca Hague or Bethany Barrus at 269-387-7060 or Helen Sharp at 269-387-8024. You may

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also contact the Chair of the Human Subjects Institutional Review Board at 269-387-8293 or the Vice President for Research 269-387-9298 with any questions or concerns that you have.

This document has been approved for use for one year by the Human Subjects Institutional Review Board as indicated by the stamped date and signature of the board chair in the upper right corner. Do not participate if the stamped date is more than one year old

Signature of Participant (Over Age 14 Years)

I understand I am agreeing to participate in a discussion about the Oral Cleft Clinic. I understand I do not have to answer every question and that I can stop at any time. I understand that even if my parent/guardian agreed, I don't have to participate.

Your signature below means that you agree to participate in a group discussion about the Oral Cleft Clinic.

Signature

Date

Permission
obtained by: _____

initials of researcher

Date

Confidentiality Agreement:

I agree not to discuss personal information or comments made by others outside of the group discussion. I understand that I will have the choice to use an alias instead of my first name during the discussion.

Signature

Date

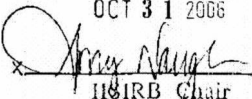
Permission
obtained by: _____

initials of researcher

Date

X Jim Nungesser
HSRB Chair

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You may withdraw your child from this study at any time without any effect on medical services to your child. If you have any questions or concerns about this study, you may contact Rebecca Hague or Bethany Barrus at 269-387-7060 or Helen Sharp at 269-387-8024. You may also contact the Chair of the Human Subjects Institutional Review Board at 269-387-8293 or the Vice President for Research 269-387-9298 with any questions or concerns that you have.

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Signature of Parent or Guardian

Your signature below indicates that you, as parent or guardian, can and do give your permission for

_____ (child's name)

to participate in a 1-1 ½ hour focus group discussion about the Oral Cleft Team with 4-5 other individuals.

Signature _____	Date _____
Relationship: _____	
Permission obtained by: _____	_____
initials of researcher _____	Date _____

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