Perceptions of Adolescents: Preferences of Adolescents for Parental Presence and the Effect on Information Disclosure

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ACKNOWLEDGMENTS

I would like to begin by thanking the person who has encouraged me, continually evaluated and improved my work, and shown immeasurable patience during this entire process, Dr. Helen Sharp. I also would like to thank the members of my graduate committee, Dr. Dilip Patel and Dr. Stephen Tasko for taking the time to review my work and provide valuable input.

Secondly, I would like to thank my family and friends for supporting me in every possible way throughout all of my schooling. Their understanding, assistance and tolerance have helped carry me through the years. I would like to thank Pete Muszkiewicz for believing that I could complete this project whenever I was consumed with doubts, and Rebecca Hague for partnering with me.

Lastly, I would like to thank the entire faculty and staff in the Department of Speech Pathology and Audiology. They have provided a wonderfully challenging educational experience that I believe will serve me well down the road.

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Adolescents born with a cleft lip or palate are in a unique position because they have received a lifetime of interdisciplinary team care where decisions are frequently made by parents, yet they are transitioning into a stage of life in which they will make their own health related decisions. Because of the complexity of their health needs, the preferred method of care is interdisciplinary team care (Nackashi, Dedlow, Dixon-Wood, 1997; Kummer, 2001). Little research has been conducted regarding the perceptions of adolescents with oral cleft about their care and issues of confidentiality in the context of team care. This study explored whether adolescents perceive that parental presence in the room affects the information they disclose to oral cleft team members, if adolescents have a preference for having a parent in the room, and if this varies by health profession.

Two focus groups were conducted with adolescents between the ages of 14 and 17 years, 11 months who have been seen in an oral cleft clinic within four years. Results indicated that parental presence does affect adolescent disclosure, adolescents may prefer that parents be present at times and excused from the room at times, and that these preferences vary by healthcare profession. These findings have important implications for understanding adolescents’ perceptions of cleft care and to develop clinical protocols to facilitate confidentiality and the transition to independence in health care settings.
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CHAPTER I

INTRODUCTION

Cleft Care

Cleft Lip & Palate

Cleft lip or palate is the most common birth defect worldwide (American Cleft Palate-Craniofacial Association, 2005). The national incidence is reported as 5.98-6.59 per 10,000 live births for cleft palate only, and 10.15-10.94 per 10,000 live births with cleft lip with or without cleft palate (Centers for Disease Control and Prevention, 2006). Clefting occurs early in pregnancy when the tissues that form the lip and/or the palatal shelves fail to fuse together and leave an opening between the oral and nasal cavities (ACP A, 2005). Cleft lip and/or palate may occur in isolation, however clefts often occur in association with various malformations or syndromes (Milerad, Larson, Hagberg, Ideberg, 1997: Shprintzen et al., 1984).

The majority of clefts are thought to be caused by a combination of genetic and environmental factors, with the risk of recurrence within a family dependent upon variables such as the number of family members who have a cleft, the closeness of these relatives as well as their race and gender, and the severity of the relatives’ clefts (ACP A, 2005).

Though a cleft lip and/or palate are frequently identified at birth, the child may encounter a lifetime of difficulties with hearing loss, speech and resonance problems, dento-facial and orthodontic issues, and psychosocial adjustment that can affect the individual throughout their lifetime (ACP A, 1996). For all ages, but particularly with
adolescents the stigma of being perceived as physically different from others can have a negative effect on self-perception (Strauss, 1997).

Team Care

Team care is generally used for working with individuals with a chronic illness because of the variety and complexity of their health care requirements, and the need for several different disciplines to work together to provide the highest quality of care (Gilgun, 1988; Halstead, 1976). For adolescents born with a cleft lip or palate, evaluation and treatment is needed from many specialists over the course of several years. Team care reduces the burden on the family by offering coordinated scheduling (Kummer, 2001; Strauss & Broder, 1985). Further, team care allows coordinated care, such as concurrent surgical procedures (Kummer, 2001; Nackashi et al., 1997).

A Cleft Palate Team has been defined as being comprised of at a minimum a surgeon, orthodontist, a speech-language pathologist, a coordinator and one other specialist (ACPA, 1993). In addition, teams often include other professionals such as an audiologist, nurse, geneticist, pediatrician, and several others (ACPA, 1996). The number of team members varies from one team to another, depending on the needs of the community and availability of team members in an area. In addition to the number and type of team members, how well the team functions as a whole is essential in providing quality care.

Team effectiveness can be determined by numerous variables, such as how well the team interacts together, the quality of the individual team member, how decisions are determined, and the role the family and individual with the oral cleft plays in the process.
Research has shown that personnel are very important to patients, and that there is a strong preference for continuity of health care providers (Canady, Means, Wayne, Thompson, Richman, 1997). In particular, adolescents who have received care over a number of years need to have a sense of continuity, trust and confidence in their health care providers to foster their sense of quality care, and growing independence (Britto et al., 2004).

Adolescent Care

Confidentiality

When working directly with adolescents and their health, Bennet and colleagues (2005) aptly stated that, “The primary goal of the consultation with an adolescent, regardless of the presenting complaint or cultural background, is to foster a relationship of trust” (pg. 436). A way to establish this “relationship of trust” is for the adolescent to feel confident that the information they disclose to their health care providers will be kept confidential. Confidentiality can be defined as “the concept that information about health care treatment and services cannot be disclosed without the permission of the person who agreed to such care” (English, 1990; Holder, 1985; Morrisey, Hofmann, Thrope, 1986). The issue of confidentiality for adolescents is highlighted in discussions regarding services for pregnancy and sexually transmitted diseases (STDs) (Ford & English, 2002; Reddy, Fleming, Swain, 2002; Thrall et al., 2000). Several studies have indicated that approximately one third of adolescents would not seek health care if parent notification was mandatory (Cheng, Savageau, Sattler, DeWitt, 1993; Klein, Wilson, McNulty,
Kapphahn, Collins, 1999). A study of girls ages 12-17 found that up to 60% of subjects reported that they would stop or delay using general health services if they knew their parents could find out (Reddy et al., 2002). These studies appear to support confidential services for adolescents because the majority of adolescents would forego health care rather than risk having personal information available to their parents.

While confidentiality is important to all adolescents, this issue may have special bearing for adolescents who live with chronic health problems such as a cleft lip and/or palate. These individuals see health care providers more frequently over their lifetime, which can emphasize the need for confidence and trust in their health care provider’s skills and professional qualities. Studies of adolescent preferences suggest that even in the stages of early adolescence, young persons with chronic illness prefer more time alone with their providers and greater confidentiality (Sanci, Sawyer, Kange, Haller, Patten, 2005; Zack, Jacobs, Keenan, 2003). The vast majority of young people with chronic illness (91%) and their parents (93%) rate confidentiality as a very important quality of health care providers (Farrant & Watson, 2004). Adolescents state a preference for physicians to communicate directly to them and rate physician trust and respect as the most important components of health care quality.

Though most health care providers would agree that providing some modified form of confidentiality to adolescents is a good idea, the process of actually doing so is complicated. There is not universal agreement among health professionals about what age adolescents should be seen alone, under what circumstances, or whether being seen alone or withholding information from parents should even be an option for minors. While the Health Insurance Portability and Accountability Act of 1996 (HIPAA) Privacy Rule was
established to clarify and protect private health information, the rule defers to state law with respect to adolescents (English & Ford, 2004). State laws vary with respect to conditions for confidentiality, however often it is left to the adolescents’ health care provider to determine the extent of confidentiality offered to the young person (Lyren & Silber, 2006). The Society for Adolescent Medicine (1997) states that confidential health services are essential, and that health care providers should be flexible when delivering confidential care, however these are recommendations, not policies. Even when confidential care services or privacy policies are established, there can be confusion within a practice or organization as to the extent of confidential services offered. For example, Akinbami and colleagues (2003) found low agreement about confidentiality practices between physicians and office staff.

Part of health care providers’ caution in providing confidential health care to adolescents is based in the relationship between the provider and the family, specifically the designated legal decision maker for the adolescent. Aside from special conditions in which adolescents are deemed legally competent to make their own decisions, parents or guardians are legally responsible for making health decisions for adolescents. While providers may want to offer confidential services to adolescents, they may fear resistance or confrontation with parents (Ford & Millstein, 1997; Purcell, Hergenroeder, Kozinetz, Smith, Hill, 1997). This can create a situation where health care providers may avoid bringing up the option of confidential services to adolescents because they do not want to offend parents. However, a study by Hutchinson and Stafford (2005) that focused on educating parents about clinic privacy policy found that most parents believed that doctors should have the option to see adolescents alone, that adolescents should be able
to speak to the doctor alone if they desire to, and that there are good reasons to have confidential information between adolescents and doctors. Of those parents who disagreed with these statements, half changed their opinion after education about teen privacy.

Ethical concerns are also an issue for the healthcare provider when determining what level of confidentiality they can extend to adolescents. Similar to working with any individual, healthcare providers should be guided by the principles of respect for autonomy, beneficence, nonmaleficence and justice (Beauchamp & Childress, 1994). However, when working with adolescents certain situations may warrant disclosure based on the information provided by the adolescent. Some decisions, such as whether to disclose suicidal ideation are more straightforward than information regarding STDs (Silber, 1989). However, any breach in confidentiality can negatively affect an adolescent’s trust of their healthcare provider and may have long-term repercussions. Ford and colleagues (2004) recommended that in order to gain the adolescents respect and trust the healthcare provider should discuss what information can and cannot be kept confidential prior to these situations occurring.

While parental opinions about adolescent confidentiality can be shifted through education, health care providers must determine what confidential services they will offer to adolescents. They also need to make these policies well known in the setting to ensure that parents and adolescents are aware of their options. For adolescents with cleft lip or palate, establishing a privacy policy that all health care professionals on the team can agree with becomes an additional challenge that must be overcome.
Transitions

When adolescents reach the age of legal majority, usually age 18 years, they are considered to be part of the adult population with social and legal responsibilities. In health care, at age 18, an individual assumes full responsibility for their health-related decisions. Ideally, this process involves a transition throughout the teenage years so that when teens turn 18 these young adults are able to be fully responsible for their health care.

A successful transition from pediatric to adult care is crucial within the population of young adults with chronic illness. There is growing concern for this issue because an increasing number of children with illnesses considered to be childhood related, such as Cystic Fibrosis, are surviving into their adulthood due to advanced technology (Gortmaker & Sappenfield, 1984; Newacheck & Taylor, 1992). According to McPherson and colleagues (2004), there are more than 9 million children with special health care needs in the United States. There is a general consensus in the literature that transition for adolescents with special health care needs is often unsuccessful (Blum, 2002; Reiss & Gibson, 2002; Viner 1999).

Unsuccessful transition to adult health care can be attributed to a variety of causes. Viner (1999) states that the transition for adolescents in pediatric settings is either “...one of transfer to adult services, or long-term retention in the paediatric clinic, or discharge from medical supervision, either voluntarily or by neglect” (pg. 271). Adolescents often feel that the transition is abrupt, that they are unprepared and are uncomfortable leaving a longstanding relationship with someone who is very familiar with the different aspects of their health problem, and that the lack or loss of insurance at
the age of 21 can also be a barrier to successful transition (Lotstein, McPherson, Strickland, Newacheck, 2005; Reiss, Gibson, Walker, 2005; Viner, 1999). Because many of these health problems are considered to be “childhood” related, there is concern about a lack of adequately trained physicians and health care teams that can handle the multifaceted health challenges of these young adults. Parents and health care providers may also overlook the transition process and fail to discuss what to expect in the future with these adolescents. Scal and Ireland (2005) reported that 50% parents of children with special health care needs reported that they had discussed transition issues with their child, but only 16% had developed a plan to address future needs. Adolescents who had addressed transition needs were generally older and had more complicated needs. Additionally, young teens and young Hispanic black children were less likely to have discussed transition needs (Lotstein et al., 2005).

The Society for Adolescent Medicine (2003) issued a position paper with recommendations to aid a successful transition for adolescents into adult care. The organization suggested that the primary care provider, along with the patient and family should take responsibility for coordinating health care, and that adolescents should be educated about transition. Additionally, they recommend that young adults should receive health services in adult health care settings, that adult services need to be more widely available, that “best practices” for specific management of diseases needs to be developed, the elimination of protocols or policies that impede timely transition, and the need for further research. It is also recommended that preparation for transition should begin in early adolescence, that this should be coordinated with the future adult staff, and perhaps most important, that family members and health care providers encourage
personal and medical independence (Viner, 1999; Reiss & Gibson, 2002). A way to encourage this growing sense of independence in the young adolescent is to offer some form of confidential services. When the adolescent is allowed to talk alone they may become more comfortable with health related information, may ask questions for clarification, and feel more invested in personal health-related issues. By encouraging adolescents to become more involved in their care, providers will also aid adolescents in their development of decision-making abilities. As time progresses and the adolescent matures, the ability to make good decisions will be important to their future health care.

Informed Consent & Decision Making Abilities

Before physicians are able to administer treatment or complete a procedure, they are required to obtain informed consent. Informed consent is based on “our respect for the autonomy, dignity, and self-determination of patients” (Bernat, 2000 pg. 614). Informed consent or informed refusal can only be given if the individual demonstrates that they have adequate decision-making capacity. Applebaum and Grisso (1988) indicate that to determine a patient’s decision-making capacity the patient must have the ability to communicate their choices, understand the relevant information, appreciate the situation and its’ consequences, and be able to manipulate the information rationally. If the patient is unable to demonstrate each of these skills, the patient is unable to truly give informed consent.

In the U.S., most state laws require that informed consent must be obtained from a parent for treatment to be provided to minors (generally under the age of 18) (Gittler, Quigley-Rick, Saks, 1990). The state recognizes that there are minors who are considered
capable of making their own treatment decisions, however the law was created to protect minors from the consequences of poor decisions (American Medical Association, 1992). In some cases, such as mature or emancipated minors, or minors seeking treatment for certain health problems, an individual under the age of 18 is allowed to give consent (Illinois Emancipation of Mature Minors Act, 1987). A mature minor is an individual who is assessed by a physician during and found to possess decision-making capacity (AMA, 1992; Committee on Bioethics, 1995). The criteria for legal emancipation of a minor varies for each state, but generally includes those who are married, in military service, have children, financially independent, have received a judicial order or the consent of their parents (AMA, 1992; Committee on Bioethics, 1995; Weir & Peters, 1997). Aside from these exceptions, an individual under the age of 18 is not considered to have the authority to make health-related decisions until proven otherwise.

Assent is a way to empower the minor to have a voice in the decision-making process, without having him bear the full responsibility of his actions. The American Academy of Pediatrics (AAP, 1995) encourages physicians to obtain assent, and to involve adolescents in all decisions to the best of their ability. However the AAP cautions that one should not solicit assent if the minors’ views are not going to be taken into consideration. While physicians are often open to obtaining assent for a treatment from adolescents, dissent or refusing treatment may be considered less acceptable. Tillet (2005) explains that there is little legal precedent regarding the rights of minors to refuse treatment when the parents have given consent, and that if legal action is pursued, the parent and healthcare provider are frequently favored. However, Lind and colleagues
(2003) make the point that allowing adolescents to consent, but not to dissent, essentially gives the adolescent no decision-making power.

While the law states that minors are technically incompetent, the literature appears to support the participation of cognitively normal adolescents in health related decisions (Gittler et al., 1990; Grisso & Vierling, 1978; Hooper, Luciana, Conklin, Yarger, 2004; King & Cross, 1989; Lewis, 1987; Melton, 1983; Weithorn & Campbell, 1982). Generally, minors below the age of 13 do not demonstrate the cognitive capacities needed for consent, however minors 15 and above often possess all the skills associated with decision-making capacity (Grisso & Vierling, 1978). Adolescents 14 years and older demonstrated that they did not differ from adults in their ability to reason and understand information provided to them in hypothetical situations (Weithron & Campbell, 1982).

The literature also supports the idea that life experience, such as dealing with a chronic illness, can mature a person beyond their chronological years (Alderson, 1993; Alderson, 2006; Gardner, 1993; Harrison, Kenny, Sidarous, Rowell, 1997; Larcher, 2005; Society for Adolescent Medicine, 1995; Weir & Peters, 1997).

By recognizing emerging or full decision-making capacity in children or adolescents and allowing these individuals to have a voice, one can encourage the development of skills necessary for making complex medical decisions later in life, and facilitate the eventual transition to where these individuals will be fully responsible for managing their health (AAP, 1995; Harrison et al., 1997). A way to facilitate this process is by extending the option of confidential services to the adolescent. This provides the opportunity for the adolescent to be more comfortable giving assent perhaps without a parent present, to begin to take more control for the decisions made and to gradually take
on the responsibilities of making decisions regarding one's own health. Alderson (2006) makes the point that each person is unique, and health professionals should attend to each adolescent individually. Adolescents should be presented with information in a manner they can understand, and if they are judged by a professional to have decision-making capacity, they should be allowed the same degree of autonomy as an adult (AAP, 1995; AMA, 1992). If a child or adolescent has decision-making capacity, a provider should request his or her preferences (McCabe, 1995). Finally, though adolescents may be able to make decisions, they should not be required to make decisions if they choose not to (Alderson, 2006; AMA, 1992).

The complexity of confidentiality, transitions and consent for adolescents makes research within these areas difficult. Because of these difficulties, there is little research that deals directly with the opinions and preferences of the adolescent. Specifically, little research has been conducting regarding adolescents preferences about confidentiality, and how this affects their interaction with health professionals.

Purpose of the Current Study

Adolescents’ preferences for the degree of confidentiality in an oral cleft team care setting are not known. The purpose of the present study is to describe the adolescent experiences and preferences for having a parent in the room, whether a parent’s presence affects their willingness to disclose information in the clinic, and whether they have a preference for which health care providers they want to see on their own. Approaches such as surveys, interviews and focus groups are legitimate ways to investigate these...
questions. Because of the qualitative nature of the question and the degree of uncertainty about the range of responses the study may yield, focus groups were selected as the method for gathering data.

**Focus Groups**

Approaches to obtaining data from individuals include individual interviews, surveys and focus groups. A focus group is a form of qualitative research that employs the format of a group interview, with a heavy reliance on group interactions (Morgan, 1997). These groups are ideally created in a non-threatening environment where individual’s perceptions on specific topics can be discussed with the facilitating influence of a moderator, who also supplies the topics under discussion (Litoselliti, 2003; Morgan, 1997). While focus groups were originally developed in the 1920’s for market research to investigate consumer decisions, in the past 20 years focus groups have been used for conducting qualitative research in the social sciences (Bogardus study (as cited in Morgan, 1996)).

Focus groups allow the researcher to collect data on the topic of interest and allow access to a wide range of information from individuals with experience or interest in a given topic. Group discussions can be conducted in less time than individual interviews, provide insight into participants’ opinions and experiences, and yield information about the complexity of these opinions or behaviors (Morgan, 1996). The group dynamic also allows for a natural way of moderating extreme views presented by a minority, focuses in on the important topics, allows discussion to flow in a natural setting, encourages brainstorming and generating ideas, provides information about how individuals are
influenced by a group, and creates a situation where individuals who can not read or write may still fully participate (Litoselliti, 2003; Robinson, 1999).

Focus groups limit the number of questions covered because in-depth discussion decreases the time available to discuss multiple issues. Additionally, group discussions can create problems with clashing or manipulative personalities, reduce opportunities for quieter individuals to speak if the session is not well facilitated, and yield results with restricted generalizability (Kitzinger, 1995; Litoselliti, 2003; Morgan, 1996; Robinson, 1999). Despite these limitations, many researchers in recent years have found focus groups effective for collecting qualitative data that serves to develop appropriate questions for use in interviews and surveys.

Focus groups were chosen over individual interviews because of the desire to observe how group interactions influence similarities and differences in opinions, to reduce the pressure on the individual to respond, and to allow other group members to bring up novel issues (Morgan, 1997). Focus groups were also chosen instead of surveys because of the desire to gain in-depth, qualitative data on adolescents’ perceptions of services received in the Oral Cleft Clinic, which will allow construction of a broader survey based on the perceptions of adolescents with oral clefts who have had experience with team care.

Summary

Clefts of the lip and/or palate are the most common congenital anomalies worldwide. Adolescents born with a cleft lip or palate have received a lifetime of medical
and dental care where decisions are frequently made by parents, yet they are entering a stage of life where they will need to make their own health-related decisions. The preferred method of care for these individuals is interdisciplinary team care, because of the complexity of their health needs. However, little research has been conducted regarding the perceptions of adolescents about confidentiality and decision-making when services are offered by an interdisciplinary team.

Research Questions

Using Focus Group Methodology to Collect Qualitative Data, the Following Questions Will be Addressed:

1. Do adolescents perceive that parental presence in the room affects the information they disclose to members of the oral cleft team?

2. Do adolescents have a preference for having a parent in the room?

3. If there is a preference, does this preference vary by health profession?
CHAPTER II

METHODS

Subjects

Adolescents from the Kalamazoo Center for Medical Studies (KCMS) Oral Cleft Clinic were invited to participate through a mailing that requested that they contact the investigators if they were interested in learning more about the study.

Inclusion and Exclusion Criteria

Adolescents between the ages of 14 and 17 years, 11 months old that were born with cleft lip and/or palate were eligible to participate. Adolescents were not included in the study if they could not converse in a group setting in English, had not attended the Oral Cleft Clinic within the past four years, or had cognitive problems that would affect their ability to give assent.

Protocol

Subject Recruitment and Procedure

Those who met the inclusion criteria were contacted through a mailing, offering them information about participating in a research study investigating adolescent perceptions. Prospective participants were asked to contact the investigators by mail or telephone if they were interested in participating. The recruitment informed prospective participants that participation was voluntary. They were informed that if they chose not to participate, it would not alter their clinical care through the Oral Cleft Clinic or KCMS in
any way. The letter detailed the purpose of the study, the length of participation (1-2 hours), and one required visit to the College of Health and Human Services building at Western Michigan University. The letter informed participants that at the conclusion of the study they would receive a twenty-dollar gift certificate to Barnes and Noble bookstores as a token of appreciation for their time and willingness to participate. Eight days after the initial letters were mailed out, a reminder post card was sent to all participants to remind them to contact the investigators to indicate their interest in participating in the study. A second mailing was then sent to non-responders for an additional reminder of the opportunity to participate in the study.

When prospective participants called, a screening interview was conducted over the telephone. If the adolescent was eligible, an intake form was completed during the initial phone conversation to gather information regarding subject availability to participate, and a contact number. Adolescents that were ineligible were thanked for their interest and encouraged to participate in future research. A list of those ineligible was maintained until recruitment was closed in order to track overall responses to the recruitment letter and to avoid repeat mailings.

Prospective participants were then offered several different dates to participate in a focus group, and were asked to choose their top two. Ten days prior to the study, the investigators sent a reminder letter to prospective participants with information about the time, date, and location for the study. One day prior to the study, the prospective participants received a reminder phone call from the investigator. The recruitment, enrollment, and respective protocol were reviewed and approved by the Human Subjects
Internal Review Board at Western Michigan University (see Appendix A for HSIRB approval).

A total of two focus groups were conducted, with two individuals attending per group session for a total of four subjects.

Consent

Prior to initiating the focus group discussion, written assent from the adolescents and consent from the parents were obtained using consent and assent forms approved by the Western Michigan University HSIRB. A description of the purpose of the study, the voluntary nature of participation, and an opportunity to ask questions preceded presenting the consent forms.

Confidentiality

After signing the assent forms, participants were given a confidentiality agreement detailing their understanding that personal information or identifying individual comments made by group members should not be discussed outside of the study. Further protections included secure maintenance of all data related to the study and the use of identification numbers in data analysis.

Demographics

After obtaining written consent, assent and a signed confidentiality agreement, participants were asked to complete a demographic form (Appendix B, Table 1 & 2) to obtain information regarding age, gender, most recent visit to the Oral Cleft Clinic, who accompanies them to the cleft clinic and general information about their visits to the Oral Cleft Clinic.
Focus Group

Warm-up Activity and Focus Group Questions

Before any formal research questions were presented, the investigator explained the format of the session. The investigator explained that the group was not expected to reach a consensus, but instead the investigator was interested in learning about multiple individual opinions. Additionally, any subject could discontinue at any time. After the format was explained, the discussion was initiated with a general question to facilitate participation and conversation between group members. Seventeen questions (Appendix C) were asked in a specific order by the investigator, with the assistance of a facilitator. Subjects were encouraged by both the investigator and facilitator to respond to each question if they were comfortable doing so. Before moving on to a new question, the investigator would summarize the information provided, and inquire as to whether any participant had anything else to add.

Data Collection

Data were recorded using audio and videotape, and transcribed into Microsoft Word. Notes were also taken by the facilitator and the investigator using flip charts, and used to clarify subjects’ intent and meaning for later analysis. Data from the intake form and demographic form were also transferred into electronic format, with the hard copies kept in a secure location to maintain confidentiality.
Data Analysis

All qualitative data was transcribed into Microsoft Word by the investigator. Data was then transferred into N6, a software program that allows for searches in qualitative data (QSR, 2002). N6 allows the investigator to select and apply search terms in order to group individual’s responses and examine these responses for common themes as well as variations in language that are used to describe similar phenomena. For example, phrases including “privacy,” “confidentiality” and “seen alone” might all go together under the grouping of desire for confidentiality. All quantitative data was entered and analyzed in Excel. Access to the computer containing data was limited to the primary investigator, committee chair and facilitator.
CHAPTER III

RESULTS

Subject Characteristics

Thirty-four letters were sent out to potential participants. Four were returned as undeliverable. Of the remaining thirty, six (20%) adolescents responded to the initial mailing. One respondent indicated that he/she did not wish to participate, and one respondent was beyond the age maximum. Four subjects were enrolled in the study; two were female and two were male. All subjects were 15 years of age. All subjects had their most recent visit to the cleft clinic within the past 24 months. All subjects stated that their parents routinely brought them to the oral cleft clinic. Demographic information is summarized in Table 1 (Appendix B).

The subjects’ degree of knowledge regarding their oral cleft and related health care varied. Three subjects stated that they felt knowledgeable about their cleft, one subject indicated that he/she asked questions when he/she visited the cleft clinic, and three subjects felt that they received answers to their questions. All four subjects agreed or strongly agreed that they already make decisions with their doctor regarding their general health and their cleft and that they would be ready at the age of 18 to make decisions with their doctor regarding their general health and their cleft.
Responses to Open Ended Questions

Do You Go to the Clinic With a Parent or Another Adult?

All subjects responded that they attended the Oral Cleft Clinic in the company of a parent.

List Some Advantages of Having a Parent With You at the Cleft Clinic.

Two themes emerged during discussion of advantages of having a parent present in the cleft clinic. First, participants valued the knowledge their parents had. Participants noted that parents ask the important questions during their visit, parents are good listeners, are more knowledgeable about the teens’ clefts, answer questions, and remember more of what was said in the clinic visit. For example, one person said, “They (parents) can answer questions that you don’t know.” A second theme raised during discussion was that parents provide moral support, such as giving the subject someone to talk to, fighting insurance companies, and carrying the file. For example, one participant said, “You can feel secure they are there if you feel uncomfortable.” For additional examples, see Appendix D, Table 3.

Disadvantages of Having a Parent Accompany Adolescents at the Cleft Clinic.

During discussion three themes emerged concerning the disadvantages of having a parent present at the cleft clinic (summarized in Appendix D, Table 4). One theme was that parents dominate the interaction. For example, participants stated that parents answer for them, the parent bothers or interrupts them when the doctor asks a direct question or as one subject stated, “Sometimes I don’t like having my mom there because she jumps
in and stuff” (Appendix D, Table 4). Additionally, subjects stated that they and their parents argue, parents talk forever, and the subjects felt that they could learn more without parents present, or as one subject said “I could probably learn more without my mom there…if Dr. X could simplify things for me then go bigger and bigger then I could learn more than I know right now” (Appendix D, Table 4).

Another theme that emerged during discussion was the lack of disclosure when parents were present. Subjects stated that they felt they could not say certain things in front of their parents, such as “Some things I can’t say in front of my mom.” In addition to a lack of comfort with disclosure some issues with parents present, non-disclosure or lies were also mentioned. For example, one subject stated that, “You can’t lie about what like you eat to the dietician.”

Finally, subjects indicated that at times they experienced difficulty interacting with their parents. For example, subjects stated that “Me and my mom don’t get along very well, we argue” and that they “…also get annoyed” by having their parent in the room. Please see Appendix D, Table 4 for more examples.

**What Are the Most Important Advantages and Disadvantages of Having a Parent With You at the Cleft Clinic?**

All subjects responded that an important advantage was parent knowledge of their cleft lip/and or palate, and the support that parents provided. Specific examples given included that the parents ask the important questions of the health professionals, and the parent remembered more of the information discussed during the visit to the cleft clinic. The surgeon was most often identified as the professional when parents’ questions were perceived as important.
When asked to rank the most important disadvantages, subjects noted that parents dominated the interaction, that parental presence caused adolescents to modify or withhold the information they provided to their healthcare providers, and that the adolescents experienced difficulty interacting with their parents. Subjects stated that they could not lie to the doctors with the parents present; felt they could not ask or say certain things in front of their parents, and that the parents would talk a lot during the visit. Other important disadvantages noted were that the parents bothered them when the doctor asked a direct question of the subject, and that the parents could be annoying.

**Would You Have Talked to the Doctors Differently if You Were by Yourself?**

Participants responded that they would have talked differently if their parent had not been in the room. For example, subjects stated, “I would have, um, like to the social worker I would have talked about boys and schoolwork” and one subject indicated that he would like to talk, “...about how certain things work for one thing and not for another and tools, activities or, tools doctors use, and kind of tools of life.” Subjects further indicated that they would have learned more about how and when surgeries were done, talked more honestly about eating habits, and perhaps would ask fewer questions since they were used to having the parent ask questions for them.

**Are There Certain People on the Oral Cleft Team That You Would Have Preferred to See by Yourself?**

Some subjects indicated that they would like to see certain people on the oral cleft team independently. Professions mentioned were social workers, orthodontists, dieticians,
and surgeons. Some participants did not have specific preferences for particular people on the oral cleft team without their parents.

How Do You Think Teens Should be Seen in the Oral Cleft Clinic?

In general, participants agreed there should be an age when adolescents should be seen in a clinical setting independent from their parents. Suggested ages when adolescents should be seen alone were 13 and 15 years old; or more generally, “When they (adolescent) feel they can” or “When you’re old enough to be responsible.” Other suggestions were included that, “instead of having a check sheet, they should get like into a group meeting,” where all professionals are in one room, and that teens should be part of the group discussion regarding their care (summarized in Appendix D, Table 5).

Is There Anything We Haven’t Talked About That You Would Like to Discuss?

Participants suggested ways to improve adolescent care. One indicated that patients should be asked biographical questions only once at the beginning of their visit and not have to repeat the information to every professional. Another suggested that professionals place a note on the door indicating whether or not adolescents can have the choice of being seen without a parent present.
CHAPTER IV

DISCUSSION

Significance of the Findings

Relationship Between Parental Presence in the Room and Adolescents' Release of Information

Responses provided by the participants in this study indicated that these adolescents are accompanied by a parent in the clinic, and that they would provide different information to their health care provider at the Oral Cleft Clinic if a parent were not present in the room. Reasons given for this were that the adolescents wanted to ask personal questions related to their body, social life (dating/life skills), and the feeling that they could learn more without having their parent present. This finding is supported by previous research that suggests that when adolescents have some form of confidentiality, the transition process to adulthood is promoted (Reiss & Gibson, 2002; Viner, 1999). Additionally, this emphasizes the importance of using assent so that adolescents feel they are involved in their health, and become used to weighing the options and forming their own opinions on treatment decisions. The findings of the current study are concurrent with previous work by Kapphahn and colleagues (1999) who found that most older healthy boys and girls preferred to be seen by their health care provider without a parent present.
Adolescents’ Preference for Having a Parent in the Room

All subjects indicated that they attended the Oral Cleft Clinic with a parent and identified both advantages and disadvantages to this structure. Their discussion highlighted that adolescents prefer that the parent was not in the room because they did not feel comfortable disclosing certain information in front of their parents and that they felt that the parent dominated the interaction. One subject noted, “I could probably learn more without my mom there.” The information provided by these subjects agrees with the theme in the literature that even from early adolescence, young people want more confidentiality (Sanci et al., 2005; Zack et al., 2003). Additionally, these subjects appeared to be unaware that they had the option of seeing a provider alone, but seemed to be waiting for someone to inform them when this was a possibility. This corresponds to Cheng and colleagues research (1993), which found that approximately only one third of adolescents surveyed were aware of their rights to confidentiality.

Participants also identified advantages of having a parent in the room and these highlight that adolescents appreciated the benefits of parent knowledge, ability to ask important questions, and the support provided by the parents. These teens recognized their own limitations in their knowledge of their history and rely on the parent to convey this information to health care professionals in the Oral Cleft Clinic. However, while subjects indicated that they appreciated having their parents in the room, they further stated that they would still like to have the option of not having the parent in the room.
Subject responses indicated that it may be that adolescents would prefer to see specific health professionals independently. Professions mentioned were: social worker, dietician, orthodontist, and plastic surgeon. In addition, during discussion of disadvantages for having a parent present, these four professions were repeatedly mentioned as professionals the adolescents would be more likely to talk to about sensitive issues they did not want to discuss in front of their parents. Subject pool size limits the interpretation of these data, so it is possible that other professionals will also emerge as further data are obtained.

Limitations

The most significant limitation of this study was the low number of subjects. Common themes began to emerge, however due to the very small sample it is unknown whether additional themes might arise with future research or if themes already identified will be emphasized. Originally, the research was going to be conducted with groups separated by gender, however due to scheduling difficulties and small subject pool, subjects were assigned to groups based on availability rather than gender. Because the individual focus groups were comprised of mixed gender, subjects may have felt inhibited in sharing opinions about issues such as dating and the physical changes associated with puberty. Also, all the subjects were from one Oral Cleft Clinic, which does not have a geneticist on staff. For teens that attend Oral Cleft Clinics that do have a
geneticist, one might imagine that talking about reproductive risks with both genders could be a sensitive issue for teens.

An additional limitation may have been the approach to gathering data. While focus groups are intended to be a starting point for gathering data and allow individuals to share information in a relaxed, group discussion this format may be more intimidating for those with quieter dispositions. Additionally, the research invitation and the structure of the study may have limited participation of adolescents who are inhibited by parents. If the sample was biased in this way it may be that adolescents who are more dependent on parental input did not participate, however, it is also possible that these teens could express an increased preference for independence and confidentiality initiated by the team. Because of the limited number of subjects, focus groups were small, which could have led subjects to feel they were more the focus of the examiners’ questions. This may have made subjects less comfortable sharing information, which would lead the results to be less generalizable (Morgan, 1996; Robinson, 1999).

Directions for Further Research

Research investigating whether having a parent in the room affects the disclosure of information by an adolescent, preference for having a parent in the room and which health professionals an adolescent would prefer to see should be continued because of the wide range of individuals affected by these issues. By gathering greater and more in-depth information from adolescents within these areas, healthcare providers can gain feedback on how their care is perceived by those who are the direct beneficiaries. This can also enable providers within the Oral Cleft Clinic to see where possible gaps in
transmission of information occurs, and determine possible areas where they may improve their services. Additionally, this type of information can be gathered from the more general population to see how adolescents who are not receiving special health services view their care.

This research also supports the need for good communication within the Oral Cleft team. If these health care professionals receive different information based on whether a parent is in or out of the room, the team members will need to account for the missed or altered information. Team members will also have to decide how to handle documentation of teens’ discussion with professionals when they are seen alone.

Future research should continue to use the focus group format with a larger subject pool so broader perspectives can be gathered and strong themes may be established. Once more concrete data is gathered about which areas adolescents with a cleft lip and/or palate express concern, researchers may learn the specific questions that need to be asked when gathering data. At that point, a survey could be generated so that a more diverse sample of adolescents could participate in the research.

In addition to using the questions generated in this study, additional questions should be developed regarding adolescents’ perceptions about confidentiality, how specific professions are viewed, and ways to improve service. A list of potential questions has been developed as a result of the current research, and could be used to expand this study or for separate research.

1. What should the confidentiality practice be at the Oral Cleft Clinic?
2. Would you want information you discussed with a professional alone to be:
   a. Documented?
b. Shared with your parent?

c. Shared with other members of the team?

3. Which professionals would you not want to see alone?

4. What are three ways the Oral Cleft Clinic/Healthcare provider could improve services for you?
CHAPTER V

CONCLUSION

This study was designed to explore whether adolescents perceive that parental presence in the room affects the information they disclose to members of the oral cleft team, adolescents have a preference for having a parent in the room, and if there is a preference, whether it varies by health profession. Literature exists concerning the struggle of individuals with chronic health conditions difficulties within the health system, and problems with transitioning to adult care. However, research investigating the preferences of adolescents with chronic illnesses towards the care they receive has only begun to emerge.

This study allowed adolescents with a cleft lip and/or palate who receive team care to discuss their preferences concerning issues of confidentiality, preferences for ways of being seen by healthcare professionals, and preferences for having a parent in the room. In addition, it provided a forum for adolescents to discuss issues that were of concern to them related to the care they receive in the Oral Cleft Clinic. The findings of this preliminary study indicate that adolescents with clefts may present information differently to their healthcare providers when a parent is in the room, that some adolescents would prefer to have the option of being seen without a parent, and that this preference to be seen alone does vary across professions with surgeons, orthodontists, social workers, and dieticians mentioned.

Future research in this area should sample a broader range of teens to gain more varied, generalizable knowledge across ages and interdisciplinary team settings. Once an
adequate base of information has been developed, specific surveys could be developed which would allow acquisition across a broader sample and allow better generalizability to inform practice. Finally, future research should focus on adolescents’ awareness of the confidentiality policy of their healthcare provider.
REFERENCES


APPENDIX A

HSIRB Protocol Clearance Letter

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

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
APPENDIX B
Demographic Information

Table 1. Demographic Profile of Subjects

<table>
<thead>
<tr>
<th>Category</th>
<th>No.</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age 14-16</td>
<td>4</td>
<td>100%</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>M</td>
<td>2</td>
<td>50%</td>
</tr>
<tr>
<td>F</td>
<td>2</td>
<td>50%</td>
</tr>
<tr>
<td>Most Recent Visit to Cleft Clinic</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-2 years ago</td>
<td>3</td>
<td>75%</td>
</tr>
<tr>
<td>Who goes with you to clinic</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mom</td>
<td>3</td>
<td>75%</td>
</tr>
</tbody>
</table>

Table 2. Scaled Items Measuring Individual Knowledge and Readiness

<table>
<thead>
<tr>
<th>Item</th>
<th>Mean</th>
<th>Standard Deviation</th>
<th>Median</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am knowledgeable about my cleft</td>
<td>1.5</td>
<td>1.32</td>
<td>2</td>
<td>-2 - +2</td>
</tr>
<tr>
<td>I ask questions when I visit the oral cleft clinic</td>
<td>.33</td>
<td>1.4</td>
<td>0</td>
<td>2 - +2</td>
</tr>
<tr>
<td>I get answers to my questions in the oral cleft clinic</td>
<td>2</td>
<td>.5</td>
<td>2</td>
<td>2 - +2</td>
</tr>
<tr>
<td>I will be ready to make decisions about my general health when I turn 18</td>
<td>1.25</td>
<td>1.66</td>
<td>1</td>
<td>2 - +2</td>
</tr>
<tr>
<td>I will be ready to make decisions related to my cleft when I turn 18</td>
<td>1.67</td>
<td>.82</td>
<td>2</td>
<td>2 - +2</td>
</tr>
<tr>
<td>I already make decisions with my doctor(s) about my general health</td>
<td>1.5</td>
<td>1.44</td>
<td>1.5</td>
<td>2 - +2</td>
</tr>
<tr>
<td>I already make decisions with my doctor(s) related to my cleft</td>
<td>1.25</td>
<td>1.66</td>
<td>1</td>
<td>2 - +2</td>
</tr>
</tbody>
</table>

Strongly Agree (2)
Agree (1)
Neutral (0)
Disagree (-1)
Strongly Disagree (-2)
APPENDIX C

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 all right 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 his or her opinion, however if you don’t want to answer a question you don’t have too.

In a minute we are going to ask you to say your first name. You have a choice to use your real first name or to use another name for the discussion today. If you’ve always wanted to be called “Elmo” today is your chance! Through the group discussion we will use the name you give us and we will only use first names. Even if you know someone in the group, please use the name they give and do not use their last name.

When you leave today it is really important that you agree not to tell people who weren’t here what other members of the group said. Of course you are free to tell your parents the themes and issues we talked about, but it is very important that everyone feel comfortable that what they say will be kept confidential. What that means is that you can’t tell your friends or parents specifics like “Guess what Katie said. She said….” It is important to maintain confidentiality because sensitive issues may be brought up during discussion. For example, someone may raise an issue, like talking with a doctor about private health care issues. We won’t know if they experienced this issue or are just raising it as something for us to consider. Either way, we want to make sure you each feel comfortable speaking freely and know that what you say will not get back to your school or others that you know. It is really important that each of you agree to keep the information we talk about here private.

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 the 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. Remember, you may use an alias instead of your real name so that no one will be able to identify you.
I’ll go first. My name is ________________, I was born in ________________, and I
like to ________________.

Thanks everyone. One thing all of you have in common is that you have been seen in the Oral Cleft clinic. We would like to hear 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 (helpful things) of having a parent with you at the cleft clinic. (Pause 2-3 minutes)

2. Using that same paper, please list some disadvantages (possible problems) 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 are some of the most important advantages?

3. What are the most important disadvantages?

**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 on 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?

Thank you for your time. I would like to remind you again that if you choose to talk about this discussion with friends or family that you talk in general about the discussion and do not use anyone’s names in reporting what people said.
APPENDIX D

Focus Groups’ Responses to Questions

Table 3. Participants’ responses to “What are the advantages of having a parent with you at the cleft clinic?”

<table>
<thead>
<tr>
<th>Subcategories</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>*Parent is knowledgable about medical issues</td>
<td>• <em>Sometimes they (parents) ask all the important questions.</em></td>
</tr>
<tr>
<td></td>
<td>• <em>They can remember more of what was said or anything.</em></td>
</tr>
<tr>
<td></td>
<td>• <em>They can answer questions that you don’t know.</em></td>
</tr>
<tr>
<td></td>
<td>• <em>My mom knows more about my cleft than I do.</em></td>
</tr>
<tr>
<td>*Parent provides support in the clinic</td>
<td>• <em>They’re (parents) good listeners.</em></td>
</tr>
<tr>
<td></td>
<td>• <em>You can feel secure they are there if you feel uncomfortable.</em></td>
</tr>
<tr>
<td></td>
<td>• <em>It can give you someone to talk to while waiting.</em></td>
</tr>
</tbody>
</table>

* Participants indicated that this was one of the most important advantages of having a parent present at the cleft clinic.
Table 4. Participants’ responses to “What are the disadvantages of having a parent with you at the cleft clinic?

<table>
<thead>
<tr>
<th>Subcategories</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>*Teens modify or omit information</td>
<td>• You can’t lie about what like you eat to the dietician.</td>
</tr>
<tr>
<td></td>
<td>• When you’re older you might not like having a parent there cause you feel uncomfortable.</td>
</tr>
<tr>
<td></td>
<td>• Some things I can’t say in front of my mom.</td>
</tr>
<tr>
<td>*Parents dominate interaction</td>
<td>• Sometimes I don’t like having my mom there because she jumps in and stuff.</td>
</tr>
<tr>
<td></td>
<td>• They bug you when a doctor is asking like, a direct question of you.</td>
</tr>
<tr>
<td></td>
<td>• They talk a lot and it takes forever.</td>
</tr>
<tr>
<td></td>
<td>• I could probably learn more without my mom there.</td>
</tr>
<tr>
<td>Difficult interaction between teen and parent</td>
<td>• They (parents) have to be in the room.</td>
</tr>
<tr>
<td></td>
<td>• Me and my mom don’t get along very well. We argue.</td>
</tr>
<tr>
<td></td>
<td>• I also get annoyed.</td>
</tr>
</tbody>
</table>

* Participants indicated that this was one of the most important disadvantages of having a parent present at the cleft clinic.
Table 5. Participants’ response to “How do you think teens should be seen in the Oral Cleft Clinic?”

<table>
<thead>
<tr>
<th>Subcategories</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Teens seen alone at a specific age</td>
<td>• <em>I would maybe say thirteen cause that’s when you’re a teen.</em></td>
</tr>
<tr>
<td></td>
<td>• <em>They (teens) should be seen alone at our age, 15.</em></td>
</tr>
<tr>
<td>Teens seen alone at an unspecified age</td>
<td>• <em>When you’re old enough to be responsible.</em></td>
</tr>
<tr>
<td></td>
<td>• <em>They (teens) should probably go when they feel they can.</em></td>
</tr>
<tr>
<td>Format of team care approach</td>
<td>• <em>I think maybe they (healthcare providers) should get into like a group meeting and say what everyone thinks, the patients, and they all make decisions that are kind of like a chain reaction.</em></td>
</tr>
</tbody>
</table>