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Coping With Cleft: A Conceptual Framework of Caregiver Responses to Nasoalveolar Molding

Dr. Lacey Sischo, Ph.D. [Postdoctoral Fellow],

College of Dentistry, New York University, New York, New York

Dr. Hillary L. Broder, Ph.D., M.Ed. [Professor], and

College of Dentistry, New York University, New York, New York

Dr. Ceib Phillips, M.P.H., Ph.D. [Professor]

School of Dentistry, University of North Carolina-Chapel Hill, Chapel Hill, North Carolina

Abstract

Objective—To present a conceptual framework of caregiver coping and adaptation to early cleft care using nasoalveolar molding.

Design—In-depth interviews were conducted at three time points with caregivers of infants with cleft lip or cleft lip and palate whose children had nasoalveolar molding to treat their cleft. Qualitative data were analyzed using modified grounded theory.

Results—Most caregivers expressed initial apprehension and anxiety about the responsibilities of care associated with nasoalveolar molding (e.g., changing and positioning tapes, cleaning the appliance). In subsequent interviews, caregivers often reported positive feelings related to their active participation in their child's treatment for cleft. These positive feelings were associated with increased self-esteem and feelings of empowerment for the caregivers. Although caregivers also identified burdens associated with nasoalveolar molding (e.g., stress related to lip taping, concerns about the appliance causing sores in their child's mouth, travel to weekly appointments), they tended to minimize the impact of these issues in comparison with the perceived benefits of nasoalveolar molding.

Conclusions—Despite the increased burden of care, many caregivers of infants with cleft used nasoalveolar molding as a problem-focused coping strategy to deal with their child's cleft. Completing nasoalveolar molding was often associated with positive factors such as increased empowerment, self-esteem, and bonding with their infant.

Keywords

burden of care; cleft; coping; nasoalveolar molding; qualitative

Having and caring for a child with cleft lip and palate (CLP), the second most common birth defect in the United States (Parker et al., 2010), is stressful in many ways (Speltz et al., 1990; Meleski, 2002; Pope et al., 2005). First, parents must cope with the stress of having a

child with a facial anomaly, which may lead to feelings of guilt, anxiety, anger, and depression (Canam, 1987; Black et al., 2009; Chuacharoen et al., 2009). In fact, research indicates that often parents of children with chronic conditions like CLP experience five stages of reactions: shock, denial, sadness and anger, adaptation, and reorganization (Drotar et al., 1975). Beyond coping with the reality of having a child who is not “normal,” parents must also endure the added care associated with CLP and other chronic conditions, which is reportedly associated with parental stress (Pope and Speltz, 1997; Hentinen and Kyngas, 1998; Meleski, 2002; Pelchat et al., 2007). Parents must devote significant time and energy organizing daily life activities as well as providing special care that includes attending frequent appointments with various medical specialists and finding and negotiating services (Pelchat et al., 2007), all of which are thought to elevate stress levels. Indeed, the care for an individual with CLP is substantial because ongoing evaluations and treatment, including hospitalizations, begin during infancy and extend over a long period of time, often into young adulthood (Snowden et al., 2003).

The impact of having a child with cleft not only affects the parents but the entire family unit, and the existence of a chronic condition, such as cleft, has the potential to profoundly disrupt the family system (Hentinen and Kyngas, 1998). In fact, one study found that divorce rates are higher in families having children with craniofacial anomalies compared with a control group (St. John et al., 2003). Other evidence, however, suggests that families of children with chronic conditions fare the same (Herzer et al., 2010) if not better than (Rodrigues and Patterson, 2007) their healthy counterparts. Nevertheless, it is clear that caring for a child with a chronic condition can have a significant impact on family structure and functioning (Locker et al., 2002; St. John et al., 2003). This effect may be influenced by the type of cleft (Kramer et al., 2007); familial characteristics such as age of the child, number of children, family income (Herzer et al., 2010), and social support; contextual factors such as family values; and cultural issues such as their worldview (Patterson, 2002).

Family and parental adjustment to the stress associated with having a child with cleft often depends on various psychosocial factors such as social support and coping, the latter of which refers to behavioral and mental efforts to handle a stressful situation (Ben-Zur, 2009). Research suggests that coping modes are related to caregivers’ (CGs’) affect: problem-focused coping (i.e., coping intended to address the problem) is associated with positive affect while avoidance coping (i.e., coping intended to ignore or avoid the problem) is associated with negative affect (Ben-Zur, 2009). The pediatric chronic condition literature has examined the effect of these coping strategies on various outcomes. For example, a recent study used a resilience model and suggested that parents of children with cleft who used problem-focused coping and had high levels of social support reported less family impact and more positive adjustment to their child’s condition than those who used avoidance-oriented coping strategies and had lower levels of social support (Baker et al., 2009). Indeed, how families and parents cope with their child’s condition impacts their stress level (Pope et al., 2005).

In addition to family impact and parental stress, the pediatric cleft literature has also explored the effect of cleft on parent-child interactions and bonding. Some evidence suggests that having a child with a cleft may have a detrimental effect on parent-child

interactions. For example, compared with controls, Murray et al. (2008) found that mothers of children with a cleft had less maternal sensitivity toward their children at 2 months of age; additionally, mothers whose children had late surgical repairs were less positively involved and looked at their children less than controls did. Yet other research indicates that “children with clefts and their mothers are doing as well as families without cleft with regard to emotional development and mother-child relationships” (Habersaat et al., 2013, p. 711). Little is known, however, about the effect of early cleft treatment on parent-child bonding. It is possible that the stress associated with initial cleft treatment, particularly the primary and/or secondary palate surgeries, affects (either positively or negatively) the parent-child relationship. For example, caring for a child after surgery, which is often stressful and difficult, may facilitate parent-child bonding or may impede existing family relationships.

Whereas initial treatment for CLP is traditionally surgical, some cleft specialists now advocate beginning nasoalveolar molding (NAM), a nonsurgical treatment, soon after birth. This is a relatively new and controversial treatment for CLP aimed at improving cosmetic and functional outcomes among children with CLP through early intervention (Grayson and Maull, 2004). The treatment, which uses surgical tape, an intraoral molding plate, and nasal stents, is typically initiated on newborns approximately 1 to 2 months of age and is completed prior to the closure of the primary palate (lip) at approximately 3 to 5 months of age. The infants must undergo this treatment for approximately 3 to 5 months (depending on cleft type and severity), requiring the CG(s) to make daily adjustments to the tape on the infant’s face as well as to attend weekly clinic appointments with the infant. Nasoalveolar molding’s principal objectives are to reduce the severity of the cleft (e.g., nasal defect, cleft size) and thereby improve future surgical results, reduce the need for other surgeries like lip and nose revisions, and minimize scarring. Both short- (4 months to 1 year) and long-term (4.5 to 12 years) studies indicate that NAM significantly improves nasal symmetry over surgery alone (Maull et al., 1999; Ezzat et al., 2007; Jaeger et al., 2007; Barillas et al., 2009; Garfinkle et al., 2011). More specifically, NAM lengthens the columella and improves nostril height and width in the presurgical phase of treatment (Pai et al., 2005; Lee et al., 2008; Nakamura et al., 2009; Chang et al., 2010).

Despite recent increases in popularity (more than one third of American Cleft Palate–Craniofacial Association teams in the United States who treat more than 25 patients with cleft each year currently offer this treatment; Sischo et al., 2011), controversy still surrounds NAM. Its opponents, for example, argue that NAM places an unnecessary emotional burden on the family system (Long et al., 2013), which already must adapt to having a newborn with a birth defect (Bradbury and Hewison, 1994; Pope et al., 2005). Given that tasks associated with caring for a child with a chronic illness, like those required by NAM, are considered stressors to parents (Meleski, 2002), it is important to understand the impact of NAM treatment on parents. Indeed, a recent study indicates that although CGs often use cleft treatment to cope with conflicting emotions about their child’s cleft, this treatment can also be a source a stress (Nelson et al., 2012).

Qualitative methodology, though not often used in craniofacial research (Nelson, 2009), is especially effective when a subject area is not well understood (Flick, 2006). Given the importance of matching the appropriate research design to the research question (Pooler,

2013) and the fact that little is known about how the care associated with NAM affects parents, qualitative methodology is particularly suited to examine CG responses to NAM (Charmaz, 2006; Pooler, 2013). This study also responds to Nelson's (2009) call that "qualitative methods be integrated into craniofacial research as part of the standard toolbox of inquiry" (p. 245). Thus, we used in-depth interviews to address the following research questions: (1) Among those CGs choosing NAM, what are their subjective responses to having a child with cleft? (2) What are CGs' subjective responses to NAM and early cleft care? and (3) How do CGs cope with the care associated with NAM and the challenges of caring for an infant with cleft?

Methods

Procedures/Sample

Caregivers of infants with either cleft lip only (CLO) or CLP were recruited at one of four well-established cleft treatment centers across regions in the United States: Children's Healthcare of Atlanta (CHOA), New York University Langone Medical Center (NYU), Oregon Health and Sciences University (OHSU), and University of North Carolina-Chapel Hill (UNC). At each study site, CGs of a newborn with CLO or CLP were asked to participate in the institutional review board–approved study. As per protocol, experienced psychosocial researchers approached CGs who had already been informed about the study by the team plastic surgeon. Before participating, as per institutional review board regulations, CGs signed informed consent forms and audio recorded consent forms. Inclusion criteria were restricted to CGs who chose NAM and provided primary care of infants less than 6 weeks of age who had nonsyndromic CLO or CLP and no other major medical issues. Caregivers with a major psychiatric disorder (e.g., schizophrenia) that might interfere with their ability to adhere to the study protocol and/or complete the qualitative interview were excluded. They were required to speak and understand English or Spanish. Spanish interpreters were used as needed, as were readers for CGs with low literacy proficiency. Because CGs who elected to have NAM treatment for their infants at the study sites and who met the inclusion criteria were enrolled into the study, the sample is considered a convenience sample.

The sample consisted of 68 consecutive CGs (17 from CHOA, 25 from NYU, 24 from OHSU, and 2 from UNC) who ranged in age from 17 to 45 years of age (30 ± 6 years standard deviation [SD]). The overall enrollment rate was approximately 75%. The study had an 88% group retention rate, which refers to the percentage of participants who successfully completed NAM treatment. Eight participants switched from NAM to traditional care prior to the second interview. For those CGs who switched treatment groups, only data from the first interviews were used in the analysis. Demographic characteristics of the sample can be found in Table 1. Data were collected at three time points in coordination with the infants' regular clinic visits: (1) 1 week after NAM insertion (at approximately 1 month of age); (2) at the presurgical evaluation prior to lip surgery (at 3 to 5 months of age depending on cleft type and severity); and (3) at the palate surgery post–op appointment for infants with CLP (at 12 to 13 months of age or a follow-up for infants with CLO at approximately 1 year of age. At each time point, CGs completed a private one-on-one

interview with an experienced behavioral/social science researcher. The interviews averaged 40 to 45 minutes at each of the three time points. The CGs received a \$50 gift card at each time point for their time and effort.

Semistructured interviews addressed various topical issues (e.g., decision making, social support, coping, health-related quality of life, contextual factors in families) based on the pediatric chronic-health literature. The questions were generally open ended with specific probe areas to ensure that similar data were collected across participants. The questions were formulated to add logic and specifics relative to the existing literature on cleft habilitation and pediatric chronic conditions. In accordance with grounded theory, the interview guides were modified during the study period based on CG responses and were varied at each data collection point.

Data Analysis

Qualitative analyses were informed by grounded theory (Glaser and Strauss, 1967; Martin and Turner, 1986; Charmaz, 2006). Grounded theory aims to induce concepts and understanding from the data, which allows for intended and unintended results. Our approach, following Burawoy's (1991, 1998, 2009) "extended case method," takes social context as its starting point and seeks to understand the wider social processes involved in a single case. This move from a specific situation (NAM treatment) to a general process (parental coping) is reliant on theory. Thus, theory guided our analysis by informing interview questions, coding, and memo writing. Consistent with the principles of grounded theory, we first coded interview transcripts. To establish interrater reliability, two of the investigators independently reviewed and coded randomly selected transcripts and then met at regular intervals to discuss codes, achieve consensus, and resolve differences. This analytical triangulation provides a critical check on interpretations to help ensure the reliability and validity of the findings (Patton, 1999, p. 1195). As the investigators coded, they also began writing theoretical memos (Charmaz, 2006). Theoretical memos were used to reflect on and develop emerging concepts and themes in ways that moved the analysis from individual CG experiences to a higher analytical understanding of burden of care, parental stress, and coping in relation to caring for a child with cleft and cleft treatment. Atlas.ti, a qualitative software package, was used to aid in data analysis (ATLAS.ti, 2012).

Results

NAM and the Process of Empowerment

Figure 1 presents a conceptual framework of empowerment based on CG experiences with NAM. Building on Gibson's (1995) definition, we define *empowerment* as a social process of recognizing, promoting, and enhancing CGs' abilities to meet their child's [cleft] treatment needs, solve any [cleft] treatment-related problems, and mobilize the necessary resources to overcome anxiety and feel in control of their child's [cleft] treatment. Although variable, the process generally consisted of CGs initially feeling anxiety or self-doubt about their abilities to complete tasks associated with NAM. After practicing and receiving social support from others, many CGs experienced increased self-efficacy about their role in NAM. As CGs completed NAM, they often provided social support to other families using

NAM and ultimately underwent positive identity construction. The driving force underlying this process was the CGs' commitment to providing the "best possible care" for their children. As one CG stated, "Even if [NAM] is a little more stressful, and your lifestyle or your day to day I think it's—you're just giving your kid the best possible care that he can get for that problem."

Initial Anxiety and Self-Doubt

After being told about the work NAM would require (e.g., positioning and keeping the appliance in place through the use of tape on their child's face, attending weekly clinic appointments), many CGs worried that they would not be able to do the tasks required of them. As one CG stated, "At first it's, you're so not sure of yourself. You know you're wondering if I'm gonna be able to do this, but time goes by and you do it, and you see the results, and it really builds up a lot of self-esteem for one's self as well. Cuz you do it, and you learn, and you do it, and it works." Some CGs even began NAM thinking that they would do their best, but if it was too difficult and incurred too much stress, they would stop NAM.

Self-Efficacy and NAM

As CGs persevered with NAM despite their initial anxiety and self-doubt, many experienced increased self-efficacy (or "people's beliefs in their ability to influence events that affect their lives" [Bandura, 2010, p. 1534]) in relation to the treatment. Caregiver self-efficacy increased through two related processes: mastery and social modeling.

Mastery—As the CGs continued to do NAM, they began to master the skills associated with the technique. With practice and positive reinforcement (from both the cleft team and the perceived change in their child's facial appearance), CGs gained confidence in their abilities. Hearing praise from the orthodontic team was particularly gratifying and inspiring for the CGs. As one CG stated:

Happy is probably in, you know, [the doctor] saying, "You're right on target."... Today, even him saying—I felt like a kid in class, but him saying, "You guys did a great job. You did what you needed"—it confirms that the trouble you did go through was worth it and you did your job as a parent, which is always a scary part. With the NAM the responsibility partly lays on the parent which is kind of—it is a little overwhelming. To hear the doctor who was working on the very device say, "You're doing a good job. You're doing what you're supposed to. It looks like it's supposed to," is rewarding.

Being told they were doing a good job and performing their NAM-related tasks correctly eased many CGs' initial anxiety and self-doubt about NAM. Likewise, seeing the improvement in their child's cleft as NAM progressed was also rewarding for the CGs. This CG's experience was typical:

It's super neat for us to—we came in today for our first follow-up appointment after he initially got fitted. He's moved in 3 mm. We could see that had moved in, and that gap had closed. We just didn't know how much. To actually see that

progress before we even come to the doctors, and you know that it's working, it's really encouraging.

Along with continuing practice, receiving positive reinforcement from the cleft team and seeing their child's improvement contributed to CG feelings of mastery over NAM-related tasks. Likewise, as their skills improved, the CGs felt more like they were a part of and in control of the NAM process.

Social Modeling—The second process that increased CG self-efficacy was social modeling. An observed benefit of the NAM weekly appointments is that CGs have regular contact with and observe other families of children with cleft. Most CGs found that seeing other families of children with cleft helped motivate them to continue NAM. During their clinic visits, CGs could look at children who had completed various aspects of treatment (e.g., NAM, lip surgery, palate surgery, and revisionary surgeries) so they had an idea of what their own child might look like as treatment progressed. Being exposed to other families showed CGs that the tasks associated with NAM were temporary and that the benefits (e.g., their child's treatment result) outweighed the cost and/or effort. Exchanges among the CGs were common in the waiting room area. For example, one CG commented:

I've found that the more exposure you have to this team and to people this team have worked with—every time I have an encounter with people here or with people who are treating their kids, my anxiety level goes down... . People whose kids are 7 years old, and who are just coming back for a little speech issue and you get to see sort of how their face ends up looking, which is always pretty good, although not always perfect. Or people who their kid is 2 months ahead of your kid.

This exposure reinforced many CGs' motivation and dedication to continuing and completing NAM.

NAM and Positive Identity Construction

Continuing with and completing NAM required performing sometimes “challenging” tasks that often led to positive identity construction and increased self-esteem among the CGs. As one CG stated, “I was scared to do [NAM] because I never do stuff like that, but actually, I feel good about it, because when I came, the doctor—they told me I did a good job. It's clean. My husband said he knew that I'm—I could do it. I feel really good.” Likewise, another CG commented, “I would say that, for me, personally, I guess, initially, I was really timid about everything, about putting [the appliance] in and taking care of it, and I was proud of myself that I was as diligent as I was.” Besides increasing self-esteem, the empowerment process also increased confidence. As one CG shared, “[NAM] helped with the overall confidence feeling. Having not had a child without a cleft, it's hard to say what things we would have been doing with that time if we hadn't been spending it with her on the NAM process. It was certainly getting through it, and feeling okay I'm competent enough to do this, to help my child. Well, that's a good feeling.”

NAM also contributed to CGs' positive identity construction by increasing parent/child bonding. The care associated with NAM requires that CGs spend extra time with the infants due to the maintenance of the appliance as well as travel to and from the weekly

appointments. Indeed, many CGs described being in a constant state of vigilance, and some CGs did not feel comfortable putting their child down for fear he or she would pull at or remove the appliance. This constant contact with their child often facilitated bonding between the CG and child. According to one CG, “I think I’ve gotten closer to him [due to NAM]. I feel like I know him a lot better and what he likes, and what he doesn’t like, and stuff like that.” Likewise, another CG stated, “There’s a bonding experience there, you’re in it together.”

Yet not all CGs shared these sentiments. Depending on their child’s reaction to and tolerance of NAM, some CGs felt like they were hurting their child:

He would see the case that we put the NAM in whenever we took it out. He would just start freaking out. He knew that we were gonna put it in, and he hated it. That was really hard as a mom, especially when I’m—cuz I was the one who had to do it. That was pretty difficult. That would be the most stressful point throughout the whole process for me.

Causing their child physical discomfort could negatively impact parent-child bonding. One CG, for example, had this experience:

Interviewer: All right. How has [your child] reacted to you since you started NAM?

Interviewee: Well, there have been times when he’s been in a bad mood when I’ve been doing [NAM] and been crying, and I feel like he’s looking at me like I’m the devil or something. That’s only been a few times. As soon as it’s over, he’s back to his normal self, and he’s happy. I mean, there have been a few times when I feel like I’m torturing him or something, but most of the time, I don’t even think he really notices.

Interviewer: How does it feel to have him looking at you like the devil?

Interviewee: Not very good. I’m worried that it’s gonna sort of scar him or something, make him turn against me or something. Then he does snap out of it, and it’s like it never happened, very quickly. That’s also why I try to do [NAM] when he’s drowsy, so he doesn’t notice. Cuz I would never want him to think that I’m trying to hurt him in any way.

Whereas such instances could potentially negatively affect CG identity, these CGs strategized and reaffirmed their parental identity by focusing on the temporary nature of NAM and their belief that the treatment was in the best interest of the child. Experiences like these were uncommon, however, and many CGs reported that the NAM actually increased their bonding with their children. Feeling close to their children helped foster a positive parental identity for the CGs.

It is important to note that a commitment to care is the driving force of the empowerment process. Our findings indicate that NAM CGs’ treatment decisions and efforts are the result of love for their children and a commitment to providing them with the best possible care. This commitment helps explain how the CGs started and continued with NAM despite early setbacks and difficulties they experienced before they received positive reinforcement and felt they mastered the skills associated with NAM. Likewise, as CGs went through NAM

and the empowerment process, the increase in self-efficacy that many felt was linked to their commitment to their child's care. The CGs felt better about themselves as parents because they were able to successfully complete NAM and give their child (what they perceived to be) the best possible treatment and outcome. Feeling in control of their child's care ultimately helped them cope with their child's cleft.

Role of Social Support

Social support often played a mediating role throughout the NAM empowerment process. This support most often came from (1) other caregivers going through NAM; (2) CGs' significant others; and (3) the doctors and/or cleft team. First, NAM families often relied on support from other families with children with cleft, particularly those families who had gone through NAM in the past (or were currently going through NAM but were farther along in the process). Caregivers often forged these relationships in the waiting room during their weekly or biweekly appointments. One CG summed up this point: "Making friends, having that weekly, Monday appointment was a godsend as far as the support system goes because being in the waiting room, you meet other families that are going through the same thing." Once they got to know one another they often shared tips, because much of the knowledge of NAM is trial and error. Families are taught the general procedure by the cleft team but often need to "tweak" it to find out what works best for their particular situation and child. Families shared tips about feeding (e.g., which bottles and nipples work best and where to find them), tape removal (e.g., using olive oil to help remove base tapes), dealing with irritated skin (e.g., using particular creams to help heal skin irritated from tape removal), and so forth. For example, one CG noted:

Of course [it's helpful] talkin' to other moms who have been through the similar situation, because if I have a question or just kind of like, "Man, this is really hard," or "I don't understand this. How long is this gonna take?" All those questions, it's good to direct it to somebody who's been there for support. I have two moms who I know that have been through the same or similar situation, who I could reach out to when I needed help with something or just needed to hear somebody else say, "I've been through it. I understand. It is gonna get better. It's hard right now but it will." Those have been the best support.

Whereas many families sought out and benefitted from this kind of interaction, not all CGs using NAM tried to foster relationships with other NAM families. Most CGs, however, did receive support from their significant others. This CG's response was typical:

My wife and I talk about it openly, the good and the bad, any thoughts, any concerns. When I say bad, I mean, like, "Are we doing this right? [laughs] Is it helping him?" Of course, when he gets a sore, you talk openly about that and all. We talk to each other, which is probably the best thing for us, because who best knows about it and is going through it?

An additional source of support for the NAM CGs was the doctors and cleft team. An important part of the cleft team approach to care is access to the treatment specialists. The doctors at each site gave families their personal cell phone numbers to call in case of an emergency, which was very reassuring for the families. As one CG stated, "At first [the

doctor] gives you his personal cell phone number. He says, “Call me, call me, call me.” At first you’re kinda like, yeah right. I don’t think I’ll call. But we’ve had to call him a couple times, and every time he’s right there. He really means it.”

Just knowing their child’s doctor was only a phone call away was comforting to the CGs and helped them continue with NAM even if complications arose.

Although these three sources of social support often mediated the empowerment process, there was still a direct relationship between anxiety/self-doubt and self-efficacy in the framework, which was exemplified by CGs who continued with NAM despite having inadequate social support. One CG, for example, had a tumultuous relationship with her child’s father and did not have close family or friends to rely on. Additionally, she spoke only Spanish and was therefore unable to create relationships with other families in the waiting room. Although she had an interpreter during her appointments to communicate with the doctors and cleft team, the language barrier was very difficult for her and kept her from receiving the social support she likely would have welcomed. Yet her commitment to her child’s care compelled her to complete the presurgical NAM appointments and in doing so, she experienced empowerment.¹ Thus, receiving social support often (though not always) mediated the empowerment process.

Whereas receiving social support mediated the initial part of the empowerment process, providing social support often mediated the latter part of early cleft care. Because other NAM CGs were often a significant source of social support, particularly in the initial stages of NAM, it makes sense that a shift would occur so that CGs who once received social support later offered it to others. This support often occurred during presurgical clinic visits when families returned to the clinic prior to lip (when the child was 3 to 5 months old) or palate (when the child is about a year old) surgery and were thus able to meet and interact with families just beginning NAM. In offering support to these families, they were paying forward the knowledge and tips they learned from other CGs and their own experience. Being able to help other families in turn helped them construct a positive identity. As one CG reported, “I like being able to help other people. This family now, when [the cleft team members] were asking me if I’d be willing to talk to them, ‘Of course.’ It’s nice to give back and help others. I know when you’re in that boat and you have questions and it’s all unfamiliar, it’s nice to have somebody to ask those things to. It feels good.”

In sum, providing and receiving social support often played an important mediating role in the empowerment process associated with NAM treatment.

There are two important caveats to note about the empowerment process, however. First, there was variability in the timing of this process. For some CGs, for example, empowerment happened quickly or early in the NAM process; whereas, for others it took more time to develop. By the end of NAM, however, most CGs had gone through this process and were pleased with their decision to do NAM. For them, NAM helped construct positive identities as people and as parents. They were able to feel good about themselves

¹Fortunately, this CG’s experience was the exception rather than the rule, given that the vast majority of CGs had what they considered to be an adequate support network.

for overcoming the obstacles of NAM (particularly their anxiety and self-doubt about being able to complete the tasks required of them) and for also being able to participate in their child's cleft care. As one CG stated, "[NAM] makes you feel good as a parent that you're succeeding."

The second caveat is that not all CGs experienced the empowerment process the same way, and some did not experience it at all. Some CGs, for example, were confident in their abilities from the beginning and so did not experience empowerment as a result of NAM—or at least not in the same way. That is understandable because highly resilient individuals have less room for improvement, which makes further growth unlikely. Going through NAM reinforced already-high self-esteem and positive identities for these CGs; whereas, for others it created self-esteem where little previously existed. Nasoalveolar molding provided a unique opportunity for some CGs to find strength they did not know they had. As one CG stated, "About myself, I guess, I've learned that I'm capable of just doing whatever I have to do. I always thought really that in our marriage my husband was the strong one. Since—in this situation, I really feel like I was because he was really not able to be around for anything because he couldn't stomach it."

Discussion

This paper presents a conceptual framework of coping and adaptation in relation to early cleft care among CGs who choose NAM treatment. By participating in their child's treatment, NAM required CGs to face the cleft, cope with their child's birth defect, and become increasingly familiar with and receive social support from family as well as cleft team members such as orthodontists, nurses, and speech pathologists. Although the care associated with NAM is rather intense, NAM-associated activities functioned as a problem-focused coping strategy for many CGs (Carver et al., 1989), which helped them manage their emotions related to their child's cleft (Baker et al., 2009; Nelson et al., 2012). Contributing to their child's cleft care made it possible for many NAM CGs to feel empowered with higher self-efficacy and self-esteem (Gibson, 1995). They often felt in control of their children's treatment, which has been shown to positively impact the psychological well-being of mothers of children with chronic conditions (Silver et al., 1995).

Whereas parents of children with other chronic conditions may often be passive observers in their child's treatment, CGs choosing NAM actively participate in their child's treatment. Indeed, the success of NAM is largely dependent on the CG's ability to follow the NAM protocol, which is a burden on the caregiver. Our findings indicate that although CGs generally began NAM feeling anxious about the process and their responsibilities, the end result tended to be positive for their psychological well-being. In fact, some CGs went through a process of empowerment as they overcame initial anxieties, often persevering through various obstacles (e.g., sores in their child's mouth, having to restrict their child's movement), to complete NAM treatment. Participating in their children's treatment has been linked to positive outcomes for CGs of children with other chronic illnesses as well (Balling and McCubbin, 2001).

This project supports previous findings in the pediatric literature that the quality of parents' social support system is positively associated with their coping and psychosocial functioning (Raina et al., 2004). Caregivers were able to start, continue, and eventually complete NAM due to social support they received from a variety of sources, including spouses, extended family members, the cleft team, and other families with children with cleft (particularly other families whose children were undergoing NAM). Because an important outcome of peer support is the feeling of shared identity and experience (i.e., knowing that CGs are not alone in their situation) (Stewart et al., 2006), it can be a valuable coping resource for CGs (Stewart et al., 1994). Like other CG populations, including those caring for children with chronic lung disease (Nicholas and Keilty, 2007), CGs in our study were better able to cope with the NAM burden of care with the support of their peers.

An additional contribution of this study to the social support literature is increased understanding of the temporal and reciprocal aspects of peer support. Our prospective, longitudinal study design allowed us to examine changes in the nature of peer support over time. The CGs often relied on peer support early in the NAM process to help them overcome initial anxiety about their ability to complete the tasks associated with NAM. As they gained confidence and reached the end of NAM, however, they often provided peer support to other CGs just beginning the treatment process. This "giving back," a coping mechanism used by CGs of children with a variety of chronic conditions (Falkenstern et al., 2009), contributed to positive identity construction and increased self-esteem for the CGs. A possible avenue of future research could include a peer support intervention that formally matches parents from the time of diagnosis with another family with a child with cleft to provide educational guidance and emotional support throughout the cleft treatment process (Nicholas and Keilty, 2007).

The CGs' experience with NAM also reveals the effect of cleft treatment on parental bonding. Our findings generally support previous research that found having a child with cleft does not affect parent-child bonding (Speltz et al., 1997; Coy et al., 2002). In fact, NAM treatment has the potential to increase bonding between CGs and their infants with cleft, although the treatment can have the opposite effect as well. Because feeling close to one's infant is an important component of a positive parental identity (Rossi and Rossi, 1990), experiencing increased bonding contributed to positive identity construction for many CGs. In sum, going through NAM granted parents a unique opportunity to bond with, take care of, and demonstrate love for their children. This is reinforced by the fact that, like Gibson's (1995) study of mothers of chronically ill children, love and commitment to care was the driving force underlying the NAM empowerment process.

Our findings also address the professional controversy surrounding NAM. Many NAM opponents claim it places too high a burden on parents who already must cope with stress associated with having a child with a facial difference. Indeed, mothers of infants with craniofacial anomalies report higher levels of stress (Speltz et al., 1990; Pope et al., 2005) and more symptoms of posttraumatic stress disorder than mothers of healthy children (Despars et al., 2011). Although parent stress may be high for parents having an infant with a cleft, the relationship between parental stress and having a child with cleft is not entirely clear. For example, some studies have found that parents of children with CLP have the

same amount of stress (Weigl et al., 2005) or actually experience less stress than other parents (Schuster et al., 2003), perhaps due to greater resilience or optimism (Strauss, 2001). The CGs in our study often expressed initial stress about NAM. Yet in being a part of the NAM process, many experienced empowerment, including greater self-efficacy and positive identity construction for the role they played in treating their children's cleft.

Despite its usefulness in dental research (Pooler, 2013), there is a paucity of qualitative research in the craniofacial field (Nelson, 2009). Our findings also contribute to the growing body of qualitative research that focuses on the subjective responses of CGs of children with cleft to their child's condition and treatment (Nelson et al., 2012; Nelson and Kirk, 2013; Stock and Rumsey, 2013). Incorporating qualitative components into research design will enhance our understanding of the spectrum of physical and psychosocial responses of this patient and CG population to NAM and other aspects of cleft care.

Based on our findings, we hypothesize that the empowerment most CGs gain through NAM will be beneficial to them in the future as their children grow older and likely face more surgery. In other words, due to NAM and possibly early cleft treatment in general, CGs have developed coping resources that will help them deal with potential problems related to their children's cleft (e.g., speech difficulties, tooth development issues, bullying) and cleft treatment. Research has found that as CGs of children with chronic conditions become more resilient, they are "better able to meet future challenges" (Rolland and Walsh, 2006, p. 528). Thus, further investigation into the psychosocial well-being that NAM provides CGs over time is warranted. The use of mixed model design using qualitative and quantitative data is recommended.

Limitations

Although this study contributes novel findings to craniofacial literature and the cleft care debate about CG burden, it is not without limitations. First, the analyses were based on a convenience sample that may not be representative of all CGs of infants undergoing NAM, although the response rate at the centers was fairly high. It is also possible that only CGs with psychosocial and personal resources choose to self-select into NAM treatment. Indeed, eight study participants did drop out or switch from NAM to traditional cleft treatment (i.e., surgery only without any molding appliance). A common reason for switching treatment categories was lack of compliance on the part of the CG. Caregivers' low adherence was based on various factors, including their children's inability to tolerate the appliance, feeding problems associated with NAM, or personal/domestic issues seemingly unrelated to NAM. Family functioning may have also played a role in CGs' decisions to stop NAM treatment because CGs with poor family functioning may not have the psychosocial resources to handle the burden of care associated with NAM (Wallander et al., 1989; Crerand et al., unpublished data, 2014). Additionally, CGs who switch to traditional care may be at risk for developing feelings of guilt and inadequacy for not completing NAM treatment. Thus, future research should study these CGs as well as screen new treatment-seeking CGs for risk factors such as family conflict, expressiveness, and/or low cohesion in order to better prepare families to deal with the NAM burden of care. Second, it is unclear whether CGs who choose to have their infants undergo traditional care also experience the

empowerment process despite their relative passivity in the treatment process. To date, scant data are available regarding the psychosocial response of these CGs to their child's cleft treatment and their adaptation over time. Future research should prospectively apply this conceptual framework and qualitative approach with CGs whose children undergo traditional care. Likewise, questions remain about the psychosocial functioning of all CGs of infants with cleft or other chronic conditions as their children age and reach various social and developmental milestones (e.g., begin school).

Conclusion

Despite the large investment of time and energy NAM treatment requires of the CGs, the care associated with NAM may indeed be beneficial by creating more opportunities for bonding with their child, as well as providing psychosocial rewards associated with mastery of a difficult task and being an active participant in their child's care. Whereas research has generally focused on the negative aspects of caregiving, evidence suggests it has important advantages as well (Green, 2007). Like Green's (2007) study of mothers of children with a disability, our findings indicate that being a CG is a complex undertaking characterized by both burdens (e.g., time- and energy-consuming care) and benefits (e.g., personal growth and increased confidence and self-esteem).

Using qualitative methodology has facilitated an unexpected positive focus regarding NAM care that has enabled new insight into the complexity of such treatment. In doing so, our findings not only address the controversy surrounding NAM and the current debate within craniofacial care related to this treatment, but they also relate to various themes within the chronic-condition and caregiving literature.

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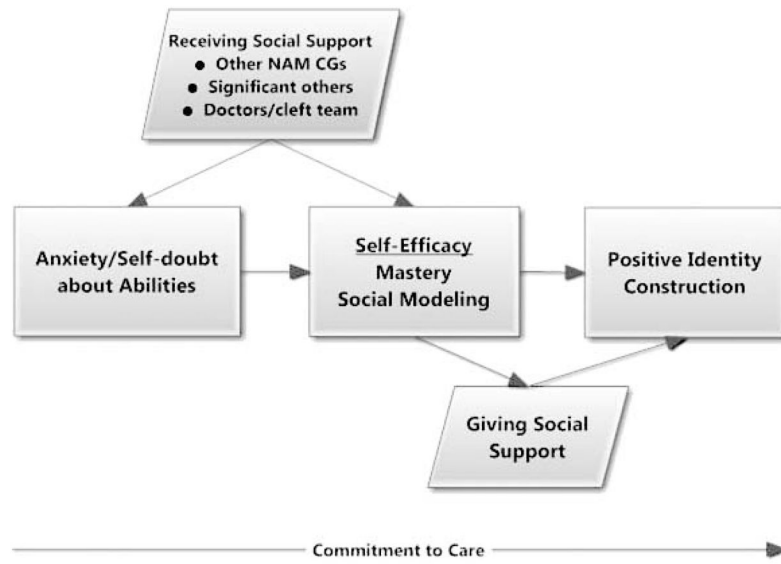


FIGURE 1.
Conceptual Framework of NAM Empowerment Process.

TABLE 1

Caregiver (CG) Demographic Characteristics

Characteristic	n	%
Gender		
Female	62	91
Male	6	9
Ethnicity		
Non-Hispanic	45	66
Hispanic	19	28
Prefer not to answer	4	6
Marital status		
Married	49	72
Single	14	21
Other/unknown	5	7
Education		
Less than high school (H.S.)	10	15
H.S. diploma/GED	12	17
Some college	16	23
College degree	19	28
Some graduate school	3	5
Professional/graduate degree	8	11
Employment		
Father (yes)	7	10
Mother (yes)	60	90
Number of children in household		
1	32	48
2	15	22
3	11	16
4 or more	9	13
Number of CGs in household		
1	8	12
2	51	75
3 or more	9	13
Combined family income		
\$25,000	20	33
\$26,000–\$50,000	11	18
\$51,000–\$75,000	6	10
\$76,000–\$100,000	12	20
>\$100,000	12	20
Child's cleft diagnosis		
Unilateral left	33	48
Unilateral right	20	29

Characteristic	n	%
Bilateral	15	23
Palate involvement		
Yes	59	87
No	8	13

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