

ECONOMIC TURMOIL AND CRANIOFACIAL CARE: THE IMPACT OF A
NATIONAL RECESSION ON CHILDREN WITH CLEFT LIP/PALATE

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ABSTRACT

ALLISON CAVENAUGH EGGLESTON, DDS: Economic Turmoil and Craniofacial Care:
The Impact of a National Recession on Children with Cleft Lip/Palate
(Under the direction of Ronald Strauss, DMD, PhD)

This study describes the impact of the recent economic recession on family financial security and health care access, with respect to multidisciplinary craniofacial treatment. Recruitment via a cleft/craniofacial parent website/email included English literate U.S. respondents with internet access, who were parents/legal guardians of a child (<18y.o.) with cleft lip and/or palate. A survey linked to the AmeriFace® website (October 2010-January 2011) collected 207 eligible responses; economic effects and perceived barriers to care were queried. Reduced income (48%), transportation costs (52%), and decreased work flexibility (35%) directly affected access to craniofacial care. Insurance premiums and co-pays/deductibles were perceived barriers independent of the economy (45% and 53%, respectively); however, the recession was seen to increase their impact (57% and 61%, respectively) and 12% lost insurance benefits entirely. Despite most participants being affluent, well-educated, and White, significant barriers to obtaining craniofacial care not only exist but have increased due to the recent economic recession.

This work is dedicated to my parents, Bruce & Alice Cavanaugh; to my brother and sister-in-law, Matt & Noelle Cavanaugh; to my in-laws, David & Mary Eggleston; to my cat, Alexander; and most of all to my amazing husband, David. I love you all.

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PREFACE

Sometimes, a single experience can alter the entire pathway of one's life; my first encounter with the UNC Craniofacial Center in 2005 has held such a lasting impression. I am always intrigued by the complex nature of the multidisciplinary treatment planning required by these patients and often touched by the length to which the families I meet go to get the best care possible for their children.

Growing up, my parents' hard work afforded me the luxury of financial comfort and stability, and as much as I wish to deny this I often took for granted the ability to purchase everything I need and even wanted (within reason). Our circumstances were humbled in April 2009 however, when the staggering economic recession forced us to close the doors of our family business. Although these unfortunate circumstances brought our tightly-knit family even closer together, my days were fraught with worry over the uncertainty of the future; chiefly, the health of my parents as they aged and their ability to access care.

One day, mulling over these worries, I thought suddenly of the patients at the Craniofacial Center. Clearly, the impact of the recession was far-reaching across socioeconomic boundaries. If these families experience obstacles to obtaining care even during periods of economic stability, how has this been affected by the recent downturn?

And thus was born my project.

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LIST OF ABBREVIATIONS

CDC.....	Centers for Disease Control and Prevention
CL/P.....	Cleft lip with or without cleft palate
COBRA.....	Consolidated Omnibus Budget Reconciliation Act
CSHCN.....	Children with Special Health Care Needs
NBER.....	National Bureau of Economic Research
OFC.....	Orofacial Cleft(ing)
SSI.....	Supplemental Security Income
US.....	United States

I. EXTENDED LITERATURE REVIEW

A gradient of disparities in access to health care exists in the United States (U.S), wherein a disparity is defined as a clinically and statistically significant difference in health care use between vulnerable and less vulnerable populations (Aday and Anderson, 1984; Braveman, 2003; Spencer, 2003; Seid et al, 2004; Kilbourne et al, 2006; Sobo et al, 2006). Vulnerable populations are considered to be those groups that have faced discrimination because of underlying differences in social status, due to race/ethnicity, gender, age, regionalization, insurance status, transient or long-term limited economic resources, literacy and health literacy levels, chronic illness/disability, and many other characteristics (Spencer, 2003; Kilbourne et al, 2006). These factors have been coined in the literature “barriers to care,” and can be viewed as a complex of sociobehavioral processes that interfere with the ability of an individual to effectively access the health care system (Seid et al, 2004; Sobo et al, 2006). A major branch of health care research aims to understand why disparities exist, identify barriers to care, and explain their influence on vulnerable populations in a way that is useful for the development of interventions that can reduce or eliminate health care disparities (Seid et al, 2003; Kilbourne et al, 2006; Sobo et al, 2006).

According to a review article by Margolis et al, three types of barriers exist to hinder use of health care services: financial, structural, and personal, all of variable importance and impact at the individual, family, and community levels. Financial barriers are often the most popularized and include issues such as insurance coverage, reimbursement, and public

support for funds allocation. Structural barriers address such topics as limited accessibility of practitioners for continuity of care, organizational aspects of primary care offices, and availability of transportation to and from appointments (Margolis et al, 1995). The topic of personal barriers, while often avoided or carefully skirted in a physician's office, may in fact have a sizeable impact on an individual's use of the health care system. These personal barriers include culture, language, attitude, education, income, expectations, knowledge and beliefs, and feelings of marginalization (Margolis et al, 1995; Seid et al, 2004).

Studies from the National Survey on Children with Special Health Care Needs have shown that affected children encounter more obstacles (financial and otherwise) in the quest for care than those without special needs (McPherson et al, 1998; Newacheck and Kim, 2005; Strickland et al, 2009). Commonly cited barriers to routine and specialty care include low household income, low maternal education levels, lack of insurance coverage, and area of low provider supply (Mayer, 2004).

In the public health arena birth defects remain an important concern, affecting not only infant morbidity and mortality but also having a substantial financial impact on the U.S. health care system. An updated national prevalence estimate for 21 major birth defects cites cleft lip with or without cleft palate to be the second most common condition (after Down Syndrome), occurring every 1 in 940 live births in the U.S. in 2004-2006 (Parker et al, 2010).

Despite the relatively high occurrence rate of orofacial clefting (OFC) there is a paucity of data in this field, and in 2006 the National Center on Birth Defects and Developmental Disabilities at the CDC developed a prioritized list of 18 research topics necessary to close critical gaps in current knowledge. Two major areas of public health

research were addressed: (1) genetic and environmental risk factors and their role in the etiology of OFC, and (2) long-term psychological and social outcomes. These areas were prioritized according to importance and feasibility by the 45 public health experts attending the workshop. The two topics receiving the most support for further research concerned genetic characterization, environmental risk factors and the translation of these into primary prevention strategies, and the third involved early screening measures for learning outcomes in affected children. Fourth on the list emphasizes quality of life as viewed by affected children, parents, and health care providers, including access to multidisciplinary team care. Closely following are topics including elucidation of associated costs (both direct and indirect), and the effect of payer status on seeking care (Yazdy et al, 2007). Among others, these aspects of care are important components of assessing the impact of OFC on affected children and their families (Strauss, 2009a).

Financial barriers studied in terms of direct medical expenses are well documented; however, indirect financial barriers as well as non-financial barriers to care are not well established (Margolis et al, 1995; Betz et al, 2004; Newacheck and Kim, 2005; Cassell et al, 2011). Some recent studies have provided updated expenditure data which broaden our understanding of medical costs for children with OFC. Two studies examined cost according to cleft type and number of services rendered, but the data only covered the first few years of life and the study design suffered some sampling limitations (Berk and Marazita, 2002; Snowden 2003). Two other studies used a national database from the Healthcare Cost and Utilization Project to study hospitalizations due to birth defects, including OFC. One of these again considered only the newborn period while the other covered a range of ages. Both found that birth defect-associated hospital stays were longer and more costly on average

than stays for non-obstetrical conditions, although actual charges for OFC were among the lowest of the birth defects studied, with neonatal costs averaging less than \$40,000 per child (Russo and Elixhauser, 2004; CDC, 2007). Two studies looked at payer expenditures and found that children with OFC incurred significantly higher health-related costs than children without OFC under both Medicaid and private insurance coverage. These studies only considered direct health-care costs by examining insurance claims and emphasized a need for additional study of nonmedical costs incurred by families due to OFC (Cassell et al, 2008; Boulet et al, 2009).

A modest number of studies have examined the impacts of OFC on children and families; however, the qualitative data to more accurately describe perceived barriers to craniofacial health care for children with OFC is lacking. One study looked at access to dental care in Alabama for children with birth defects in which 24% had cleft lip and/or cleft palate. Although 85% received routine dental care, 35% of parents reported difficulty in seeking this care. In contrast to previous reports, this study found no statistically significant difference in receiving routine dental care between insured and uninsured children; however, parents of children with Medicaid insurance were twice as likely to cite problems in obtaining dental care. The remaining 15% of parents who claimed their child did not receive regular dental care most commonly attributed this to the provider's unwillingness to treat their child, lack of insurance acceptance, and feeling overwhelmed by all the aspects of their child's disability. Other reasons were also cited such as time taken from work and school and lack of transportation. This study gives valuable insight into dental care for a child with special health care needs, but dental care is only one portion of the multidisciplinary treatment required for a child with OFC (Al Agili et al, 2004).

A recent study examined maternal perspectives of perceived barriers to care for children with OFC using a combination mail/phone survey distributed to the parents of all children with OFC registered in the North Carolina Birth Defects Monitoring program between 0-6 years old. Thirty-three percent of respondents in this study reported problems obtaining primary craniofacial care for their child, although 88% felt that their child received all the care he or she needed within the past year. The authors suggested this discrepancy could be due to demographic differences in age, diagnosis, and family support structure. Reported problems obtaining care were also attributed to structural barriers such as lack of availability of providers, referral systems, and/or awareness of coordinated care for the family unit. While this study provides valuable insight to maternal perspectives on barriers to obtaining craniofacial care, the sample was from one state only, limiting the generalizability of the findings (Cassell et al, 2011).

Overcoming this limitation by obtaining a national sample has become increasingly difficult and costly in recent years due to declining response rates, increasing postage costs, and anti-telemarketer litigation (Couper, 2007). As an alternative many researchers have turned to Internet-based surveys, which are considered accurate and reliable if designed and conducted properly, however with inherent limitations and strengths (Atienza et al, 2007). This method allows for the recruitment of a large sample unrestricted by temporal or geographic barriers at a much lower cost than traditional survey techniques. It is imperative, however, that research design fundamentals are not lost in the construction of such studies and that investigators remain cautious in their generalizations and inferences of their findings (Risko et al, 2006; Ahern, 2007; Couper, 2007). Internet sampling does not lend itself easily to hypothesis testing using classical biostatistical tests.

A large part of research design concerns creating and maintaining an equilibrium between maximizing external validity while upholding internal validity (Eysenbach and Wyatt, 2002). A fundamental principle of web-based surveys can also compromise the external validity of the study: an individual needs at least one-time internet access and basic technological literacy to even participate (Ahern, 2007). Individuals who lack Internet access also tend to have lower income and education levels, although this disparity has been decreasing steadily across socioeconomic boundaries since 2000 (US Department of Commerce, Economics and Statistics Administration, 2002; Ahern 2007). Their exclusion therefore affects the generalizability of the findings to the extent that they differ from members of the target population who have Internet access (Ahern, 2007; Couper 2007).

A major threat to the internal validity of a web-based survey is the possible lack of adherence to the established sample inclusion and exclusion criteria, as this method affords little control with regard to verification of subject eligibility (Risko et al, 2006; Couper, 2007). Suggested techniques to minimize this bias include employing cookies or IP addresses to eliminate duplicate responses; explaining criteria for participation in recruitment letter and verifying these criteria with questions throughout the survey; and placing the survey and/or recruitment advertisements in targeted areas or websites (Risko et al, 2006).

One such targeted website is that for the organization AmeriFace®, www.ameriface.org. AmeriFace® is an organization of cleft and craniofacial advocates founded in 1991 to provide emotional, educational, and practical support to people with craniofacial differences and their families. According to their website: “Services include referrals to qualified cleft/craniofacial teams, access to educational materials about these medical conditions, emotional support for affected individuals and their families, a campaign

to promote general public awareness about facial differences and the networking of individuals and families for support purposes... a nationally-recognized program offering a toll-free support hotline, on-line support forums, comprehensive websites, newborn outreach programs at area birthing hospitals throughout the country, an annual family conference and periodic newsletters” (www.ameriface.org/about.html). AmeriFace® has a history of hosting craniofacial-related surveys on their homepage, and has member listservs which are valuable for recruitment purposes.

From December 2007 to June 2009 the United States economy was officially in a recession according to the National Bureau of Economic Research (NBER), making it the longest post-Depression economic downturn, and recovery remains sluggish with high unemployment and foreclosure rates (NBER, 2008; NBER, 2010). This has prompted an interest in the association between economic stability and health care utilization. A meta-analysis in 2008 found a gradient of access to care exists even within disadvantaged socioeconomic groups (Reid et al, 2008). This was attributed to the theory of competing priorities by Gelberg which states that individuals lacking financial stability may prioritize basic survival needs above access to health care (Gelberg et al, 1997; Reid et al, 2008). This progressive inverse relationship between financial security and health care access may have a unique impact on the multidisciplinary care required for cleft patients.

This study aims to describe the association between financial security and health care access and their impact on multidisciplinary OFC treatment in the context of the recent economic recession.

II. MANUSCRIPT

Introduction

In the public health arena birth defects remain an important concern, regarding not only infant morbidity and mortality but also the substantial financial impact these conditions have on the health care system. An updated national prevalence estimate for 21 major birth defects cites cleft lip with or without cleft palate to be the second most common condition (after Down Syndrome), occurring every 1 in 940 live births in the United States in 2004-2006 (Parker et al, 2010). Despite this high occurrence rate there is a paucity of existing data in this field, and in 2006 the National Center on Birth Defects and Developmental Disabilities at the CDC developed a prioritized list of 18 research topics necessary to close critical gaps in current knowledge. Fourth on the list emphasizes quality of life as viewed by affected children, parents, and health care providers, including access to multidisciplinary team care. The list also includes elucidation of associated costs (both direct and indirect) and the effect of payer status on seeking care (Yazdy et al, 2007).

These factors are pieces of a larger concept termed “barriers to care,” which can be viewed as a complex of sociobehavioral processes that interfere with the ability of an individual or family to effectively access the health care system (Seid et al, 2004; Sobo et al, 2006). Studies from the National Survey on Children with Special Health Care Needs have

shown that children with special health care needs and encounter more obstacles (financial and otherwise) in the quest for care than those without special needs (McPherson et al, 1998; Newacheck and Kim, 2005; Strickland et al, 2009). Financial barriers include direct medical expenses which are well documented; however, financial barriers in the form of indirect costs as well as non-financial barriers to care are not well established (Margolis et al, 1995; Betz et al, 2004; Newacheck and Kim, 2005; Cassell et al, 2011). Non-financial barriers can be personal (cultural, psychosocial) or structural (related to structure of health care system) (Margolis et al, 1995).

The qualitative data needed to provide a complete picture of perceived barriers to craniofacial health care for children with orofacial clefting (OFC) is lacking. One study looked at access to dental care in Alabama for children with birth defects including OFC, but dental care is only one portion of the multidisciplinary treatment required for a child with a cleft (Al Agili et al, 2004). A recent study examined maternal perspectives of perceived barriers to care for children with orofacial clefts but the sample was from one state, limiting the generalizability of the study (Cassell et al, 2011).

From December 2007 to June 2009 the United States economy was officially in a recession according to the National Bureau of Economic Research (NBER), marking it the longest post-Depression economic downturn, and recovery remains sluggish with high unemployment and foreclosure rates (NBER, 2008; NBER, 2010). This has prompted an interest in the association between economic stability and health care utilization. A meta-analysis in 2008 found a gradient of access to care exists even within disadvantaged socioeconomic groups (Reid et al, 2008). This was attributed to the theory of competing priorities by Gelberg which states that individuals lacking financial stability may prioritize

basic survival needs above access to health care (Gelberg et al, 1997; Reid et al, 2008). This progressive inverse relationship between financial security and health care access may have a unique impact on the multidisciplinary care required for cleft patients.

This study aims to describe financial security and health care access and their impact on multidisciplinary cleft and craniofacial treatment during an economic recession.

Methods

A cross-sectional web-based survey containing multiple choice, Likert scale, and open-ended questions was developed to obtain demographic information on OFC parents and children along with parental perception of barriers to obtaining craniofacial care for their child both in general and with respect to the recent national economic downturn. The survey was pilot-tested with ten families at the University of North Carolina Craniofacial Center. The survey was approved by the University of North Carolina Biomedical Institutional Review Board, and can be viewed in the Appendix.

From October 26, 2010, to January 31, 2011, the survey was accessible through the AmeriFace® website to identify barriers to craniofacial health care for children with cleft lip and/or cleft palate (OFC) in the U.S. AmeriFace® placed a link to the survey on their website and sent an email to their member listservs to explain the survey and encourage participation. AmeriFace® is an organization of cleft and craniofacial advocates founded in 1991 to provide emotional, educational, and practical support to people with craniofacial differences and their families, www.ameriface.org. Clicking on the website link presented the potential participant with a thorough disclosure of information relevant to the decision to participate in

the survey. Three reminder emails were sent until receipt of 200 eligible surveys. Potential participants not on the AmeriFace® listservs were also able to access the survey by simply visiting the AmeriFace® website homepage, which they found either by web-surfing or by word of mouth from previous participants.

Survey responses were included if the respondent was a parent/legal guardian of a child (under 18 years old) with a cleft lip and/or a cleft palate; had internet access for a one-time survey completion; was able to read the English language; and was a resident of the United States. In addition to listing these criteria in the recruiting emails and in the disclosure information accessed upon clicking the link on the AmeriFace® website, the first four survey questions were demographic in nature (child age and diagnosis, participant's relationship to child) and served as an additional confirmation of appropriate enrollment. The participants were also asked their state of residence to ensure inclusion of only those living in the United States.

Descriptive statistics were determined for all variables including demographics, financial security and perceived problems in accessing care. Parental perception of access to care was assessed through two open-ended questions and two separate Likert scale questions. The first Likert scale question asked the participant to rate the extent the downturn of the economy (as represented by 12 Likert items) had affected their ability to access craniofacial care. For analysis purposes, a response of "no change" was categorized as "not a perceived barrier" while responses of "slight," "moderate," or "substantial change" were combined under a single category of "change," indicating a perceived barrier to care. The second question asked the participants to indicate which of 17 items had been issues in accessing craniofacial care, past or present. For analysis purposes, responses of "never" or "almost

never an issue” were combined and categorized as not a perceived barrier while responses of “sometimes,” “often,” and “almost always an issue” were combined and considered to be perceived barriers to care. Financial security was assessed throughout the survey by seven Likert questions, as well as five open-ended and two multiple choice questions. Additionally, two multiple choice questions and six Likert questions addressed health insurance status and costs as an indicator of financial stability.

Results

A total of 207 eligible surveys were analyzed with 74 surveys excluded due to lack of completion, duplicate IP addresses, and/or the age of the affected child reported as over 18 years. Ages of children with CL/P ranged from one week to 16 years old. Ages of respondents ranged from 20-56 years old, with a mean age of 36 years. A majority of the children were White (77%); the next most represented race was Asian with 15%. The respondents were primarily married (85%) and earned an annual yearly household income \geq \$50,000 before taxes (63%). Fifty-nine percent of participants had a college degree and only 1% did not hold a high school diploma or equivalent (Table 1).

Figure 1 illustrates the extent to which respondents perceived the economic downturn to have negatively impacted their access to craniofacial health care for their child in hierarchical order. Nearly half of respondents (48%) had suffered a decrease or total loss of income which created a direct barrier to obtaining cleft-related care. While the cost of health insurance premiums (57%) and deductibles/co-pays (61%) were the most commonly identified economic barriers, other associated costs also held a widespread effect. Fifty-two percent of parents claimed transportation costs to and from appointments have become more

of an obstacle to obtaining care. Other widely perceived barriers included loss of flexibility relative to work hours (35%) and an increase in insurance denials (31%). Cuts to government and/or community services negatively affected the ability to obtain cleft-related care for 26% of respondents, and 12% reported their affected child losing their health insurance altogether due to the economic downturn.

Unrelated to recent national economic changes, many participants perceive to have at some point experienced barriers to obtaining craniofacial-related health care for their child (Figure 2). Missing work for appointments was the most common obstacle reported (57%). Closely following was the cost of health insurance co-pays and deductibles; 53% viewed this as an issue independent from the recent national economic changes. Slightly less than half considered distance traveled to medical appointments (48%), insurance denials (47%), and cost of health insurance premiums (45%) significant barriers to obtaining their child's care. Financial concerns other than direct costs of medical care were perceived as barriers by a number of respondents, including transportation (29%), overnight lodging (23%), and other travel expenses (29%). Nineteen percent reported issues finding a doctor/team that would treat their child although 93% claim to be followed by a cleft or craniofacial team.

Family, budgetary, and household matters are complex issues difficult to capture by multiple-choice or even Likert scale questions. This study encouraged open-ended responses to explain how the economy had affected each respondent and their family. Qualitative analysis revealed three main themes in response to the question "Please tell us how your family has been affected by the recent economic downturn."

The first, mentioned by 57% of respondents, was "Loss of Income." This was divided into several subcategories including lost job, hours or pay reduction or business

owner seeing decreased business, salary freeze, difficulty finding employment, loss of income due to caring for a Child w Special Health Care Needs, and job change resulting in reduced salary.

The second theme, reported by 22% of respondents, concerned difficulty with health benefits and/or government assistance. This was further categorized into complete loss of benefits; government assistance programs changes or freezes; increased insurance costs, increased coverage denials, and stricter stipulations; insurance dictating employment opportunities; and change in craniofacial team/surgeon due to economy.

The final theme, cited by 23% of parents, was general lifestyle and financial difficulties. These could be serious or minor and included a parent or older child obtaining additional employment to support the family as well as stress associated with uncertainty of what the future holds for their family and their ability to access craniofacial care.

Discussion

Ratification of the Affordable Care Act (Obama Care) in March 2010 initiated a sequence of health care reforms. Although the ultimate collective goal of this act is to lower medical costs while improving quality of care for all Americans, the breadth of these controversial policies will not be universal for several years, and uncertainty exists about how much of this act will be implemented due to highly variable public and political opinions. Therefore, it is imperative in today's political climate that clinicians remain aware of the obstacles experienced by their patients in the pursuit of health care and that they seek to educate policy makers about the barriers experienced across diagnostic, regional, and socioeconomic boundaries. This study aimed to describe how the recent national economic

downturn has affected the ability of families to access care for their children affected by OFC.

A critical aspect to consider when illustrating the barriers these parents perceive to obtaining craniofacial care is the change in family dynamics, however minor, that accompanies the birth of a child with OFC. An OFC child requires parental education on specialized feeding practices and multiple physician visits with respect to future surgical repair. Some families (11% of this sample, from open-ended responses) make arrangements for one parent to stay at home to care for their child; some plan to return to work after a few years while others must take permanent leave to care for a child with complex functional and medical needs. These families depend heavily on the remaining income and benefits; the recent volatile economy therefore presented an elevated threat to their household budgets, as described by this 32 year old mother from Indiana on October 27, 2010:

“I was forced out of a job due to my son’s medical condition. I currently get unemployment that runs out in June of 2011... Our income went down, and our co-pays went up. We pay more out of pocket for our son’s medical care now as well. We are in collections with 5 different medical facilities due to his medical conditions and a recent broken arm.”

In open-ended responses on this survey, nearly half of the participants (43%) cited additional general financial difficulties due to salary freezes or hour reductions coupled with a steadily increasing cost of living. Parents experiencing such budgetary stress may feel the need to prioritize basic needs of their family above obtaining craniofacial health care for their affected child, as proposed by Gelberg’s theory of competing priorities (Gelberg et al, 1997).

Often those caregivers who opt to stay home with their affected infant intend to return to work when the child is old enough to attend daycare or school. While this is not a new development, the high unemployment rate and scarcity of opportunities due to the recent economic downfall left nearly three quarters of parents in this study unable to resume employment (70%, according to open-ended responses) after taking a childcare leave. The budgetary stress and resulting competing priorities for these families will, at best, continue until employment is obtained or, at worst, intensify as any emergency funds dwindle, as passionately illustrated by this 47 year old mother from New Jersey:

“My husband’s family has owned a car dealership for over 50 years. With the implosion of the car industry, the factory has shut them down... Our entire lives have been turned upside down and we take things day by day. We have health insurance—where we can go out of network—but hey deny, deny, deny... I could go on and on and on. We have some money left but we’re draining our accounts to get our kids the care WE know is best.”

Of those parents who have maintained or found new employment, 35% of them claimed decreased work hour flexibility had introduced a challenge in scheduling and attending appointments for their child.

It is well documented that direct medical expenses and insurance-associated costs impose a major access barrier among children and children with special health care needs (Margolis et al, 1995; Betz et al, 2004; Newacheck and Kim, 2005; Cassell et al, 2011epub). While 45% and 53% of respondents reported insurance premiums and co-pays/deductibles, respectively, as barriers to care regardless of the economic climate, the effects of the

recession elevated the impact of these burdens for 57% and 61% of respondents, respectively. As explained by this 24 year old father from Alabama:

“Wife/Mother lost job due to school proration cuts. Insurance premiums increased, co-pays increased, deductibles increased. Could not afford group plan. Applied for low cost/state policy to cover cleft and related issues and encountered problems with 1 year waiting periods, pre-existing condition clauses.”

Even more concerning is that during the recession, 12% of respondents reported that their child lost health insurance altogether. This is in addition to 7% reporting loss of children with special health care needs benefits and 4% reporting loss of Medicaid and/or Supplemental Security Income (SSI) benefits.

Despite these reported losses, only 2% claimed their child to be completely without health insurance. According to the Kaiser Family Foundation on Medicaid and the Uninsured, the percentage of uninsured children actually declined slightly from December 2007-December 2010, largely due to increasing eligibility and enrollment in public insurance programs. During this time period, Medicaid enrollment increased by a total of 31.8% for children and 28.3% for adults (some states classify “disabled” children as “adults” for record-keeping purposes) (Kaiser Commission on Medicaid and the Uninsured, 2011a; Kaiser Commission on Medicaid and the Uninsured, 2011b). Also the Children’s Health Insurance Program Reauthorization Act of 2009 provided incentives and support for states to actively enroll eligible and otherwise uninsured children in government-funded programs (US

Department of Health and Human Services, 2010; Kaiser Commission on Medicaid and the Uninsured, 2011a).

Another possible explanation for this discrepancy could be coverage through the Consolidated Omnibus Budget Reconciliation Act of 1985 (better known as COBRA) following a job loss or while between jobs (which we unfortunately did not include as an option). As the former employee is no longer subsidizing a portion of the premiums the parent may perceive this as “total loss of insurance,” but may classify their child’s insurance status as either obtained through an employer or as privately purchased. Despite a temporary subsidy reducing the cost of COBRA by 65% for workers laid-off during the recession, this relative increase in premium expense also can introduce a strain on the family budget.

Less frequently reported barriers included other indirect costs of obtaining craniofacial health care, such as out-of-pocket expenses. Of particular note is the cost of transportation, which has increased as a barrier from 29% of respondents pre-recession to 52% as a result of the recession. The cost of gasoline in 2007 alone rose by 32%, and while it has fluctuated somewhat over subsequent years, supply and demand keep oil prices significantly elevated (Orszag, 2007). As 48% of respondents considered distance from home to medical appointments an issue in obtaining care for their child, it follows that the price of transportation was also perceived as a barrier to care as described by this 38 year old mother from Washington state:

“Due to our daughter’s medical needs I don’t work anymore. It is too hard to maintain a job when you are going to Dr’s appts three to four times a week. Thankfully that was only the

first 1 ½ years of her birth. But we were very stressed for money to cover the expenses to get her to her Hospital (2 ½ hours away, by ferry) and covering gas.”

The online survey method for data collection is relatively new but is considered accurate and reliable if designed and conducted properly, however with inherent limitations and strengths (Atienza et al, 2007). One limitation is the possible lack of adherence to the established sample inclusion and exclusion criteria, which could affect the internal validity of the findings. Although online surveys present the potential for recruitment of a sample unlimited by geographical boundaries, little control is afforded with regard to verification of subject eligibility (Risko et al, 2006; Couper, 2007). In addition to the respondents' confirmation of their inclusion as part of informed consent for this study, an additional layer of selection was employed within the survey in the form of demographic and diagnostic questions (Risko et al, 2006). Placing the survey on a OFC parental support and advocacy website also served to target the population of interest and to hopefully discourage non-eligible responses (Risko et al, 2006). AmeriFace® was chosen as the vehicle for this survey because of the ability to access a national sample and due to the success of previous projects utilizing this approach (Strauss et al, 2009b).

The requirement of Internet access for this and all online surveys also potentially introduces certain biases and limitations in the sample population with regard to elevated annual household income, parental education level and possibly race. Individuals who lack Internet access also tend to have lower income and education levels, although this disparity has been decreasing steadily across socioeconomic boundaries since 2000 (US Department of Commerce, Economics and Statistics Administration, 2002; Ahern 2007). Their exclusion

therefore affects the generalizability of the findings to the extent that they differ from members of the target population who have Internet access (Ahern, 2007; Couper 2007). While the majority of the sample classified their race as White (77%), this accurately reflected the national population according to the United States Census Bureau, which reported the White population as 72.4% in 2010 (US Census Bureau, 2010). Spanish speakers were excluded from the sample because the survey was only available in English. White, followed by Asian populations are also known to have a higher prevalence of OFC compared to other races (Croen et al, 1998; Hashmi et al, 2005; Gundlach and Maus, 2006).

Conclusion

Despite the majority of respondents being affluent, well-educated, and White, our study demonstrates that barriers to obtaining craniofacial care for a child with OFC not only still exist, but have progressively increased due to the recent economic recession.

Table 1. Demographic information for child and respondent.

Total N varies per question; percentage based on number of respondents who answered each question. Total N for each question represented in parentheses. For study, N=207.

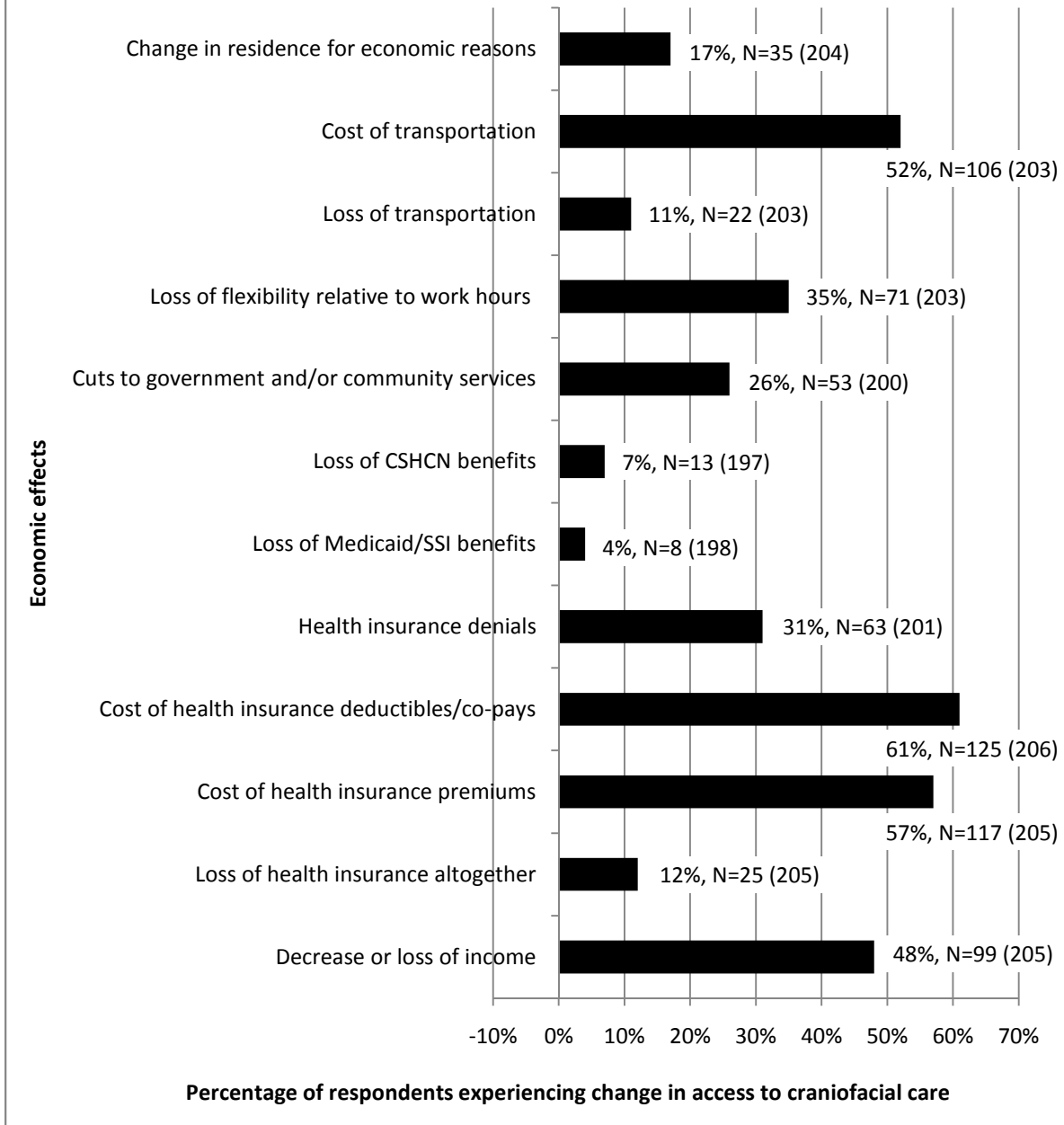
*All “other” responses were specified as some combination of the above choices.

‡ All “other” responses were specified as either American Indian (N=1, <1%) or Native Hawaiian/Pacific Islander (N=2, <1%).

Demographic/Characteristic	N	Percentage
Age of Child in Years (N=207)		
0-2	70	34%
3-5	56	27%
6-10	63	30%
>10	18	9%
Type of Cleft (N=207)		
Unilateral cleft lip only	14	7%
Unilateral cleft lip and palate	84	41%
Bilateral cleft lip only	7	3%
Bilateral cleft lip and palate	58	28%
Cleft palate only	29	14%
Other*	15	7%
Race of Child (N=204)		
White	158	77%
African American	3	2%
Asian	26	13%
Mixed/multiracial	14	7%
Other ‡	3	<1%
Age of Respondent in Years (N=199)		
<25	10	5%
25-34	79	40%
35-44	81	41%
≥45	29	14%
Relationship to Affected Child (N=207)		
Biological Mother	171	83%
Step-Mother	2	1%
Adoptive Mother	27	13%
Biological Father	5	2%
Adoptive Father	1	<1%
Non-Parent Legal Guardian	1	<1%
Marital Status (N=205)		
Married	174	85%
Divorced/Separated	14	7%
Never Married	14	7%
Non-Married Couple Member	3	1%

Demographic/Characteristic	N	Percentage
Education Level of Respondent (N=206)		
Some high school	2	1%
High school grad/GED	16	8%
Some college/technical school	67	32%
4 year college degree or higher	121	59%
Total Annual Household Income (N=204)		
<\$20,000	17	9%
\$20,000-\$49,999	58	28%
≥\$50,000	129	63%

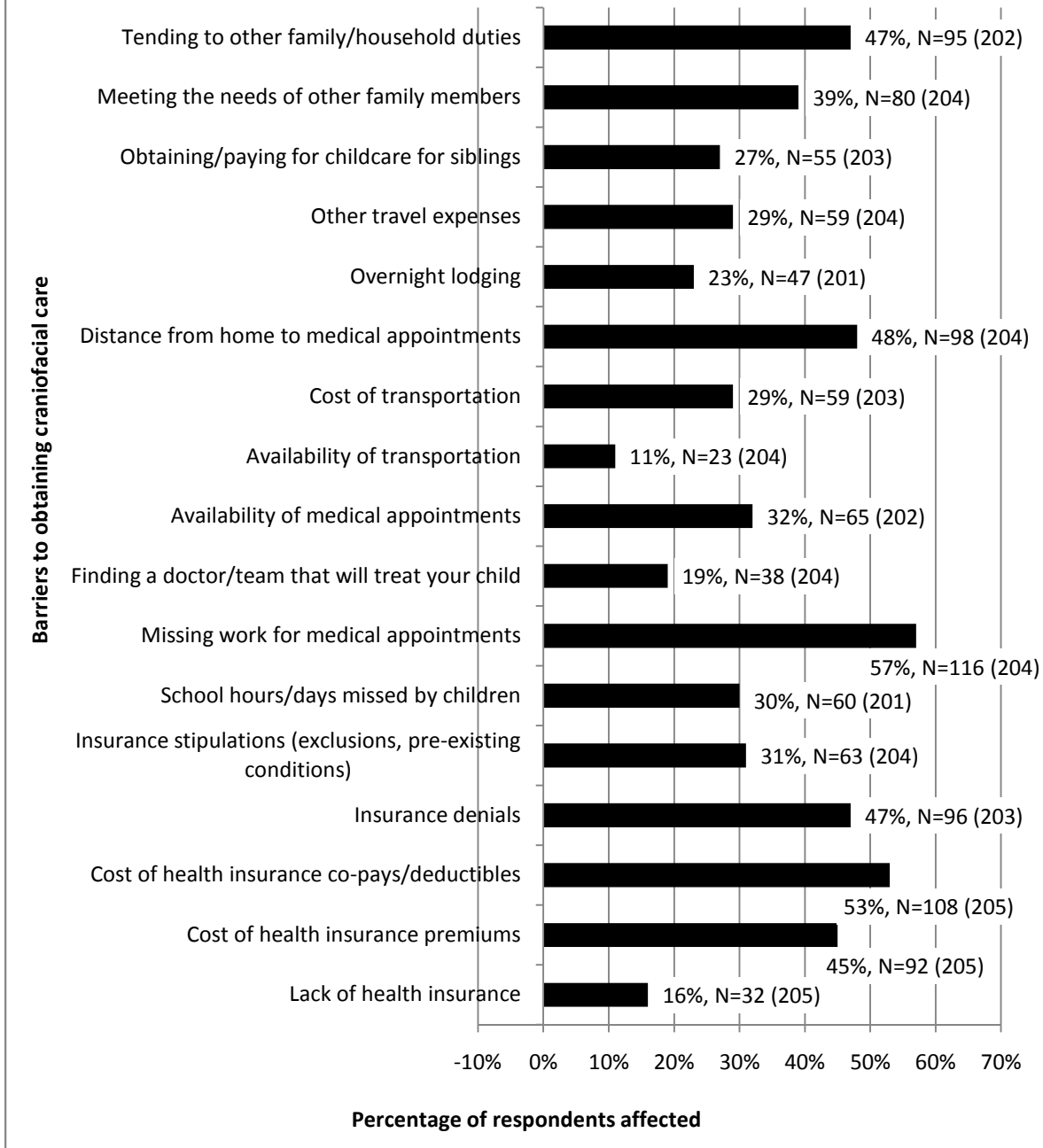
Figure 1. Negative impact of economic downturn on access to craniofacial care



*Total N varies per question; percentage based on number of respondents who answered each question. Total N for each question represented in parentheses. Respondents could “check all that apply.”

** For analysis purposes, a response of “no change” was categorized as “not a perceived barrier.” Responses of “slight,” “moderate,” or “substantial change” were combined under a single category of “change,” indicating a “perceived barrier to care.”

Figure 2. Barriers to accessing craniofacial care experienced unrelated to economic downturn



*Total N varies per question; percentage based on number of respondents who answered each question. Total N for each question represented in parentheses. Respondents could “check all that apply.”

** For analysis purposes, responses of “never” or “almost never an issue” were combined and categorized as “not a perceived barrier.” Responses of “sometimes,” “often,” and “almost always an issue” were combined and considered “perceived barriers to care.”

APPENDIX: ONLINE SURVEY

Thank you so much for joining us in this survey.

AmeriFace[®] and the University of North Carolina seek to learn more about how economic hard times and the recession have impacted your experience in obtaining medical care for your child with a cleft lip and/or a cleft palate.

If you have a child under 18 years old with a cleft lip and/or a cleft palate, please check here and proceed: _____

If you ***do not*** have a child under 18 years old with a cleft lip and/or a cleft palate, please exit this survey. Thanks so much.

Now, please tell us about ***your youngest child with a cleft lip and/or a cleft palate:***

What type of cleft lip and/or cleft palate does this child have?

- Unilateral (one side) cleft lip only
- Bilateral (both side) cleft lip only
- Cleft palate only
- Unilateral (one side) cleft lip with cleft palate
- Bilateral (both side) cleft lip with cleft palate

Other, please specify _____

How old is this child with a cleft lip and/or a cleft palate: _____ years old

What is your relationship to this child?

- Biological mother
- Step-mother
- Adoptive mother
- Biological father
- Step-father
- Adoptive father
- Non-parent legal guardian
- Other, please specify _____

Which would you say is the race of this child?

- White
- Black/African American
- Mixed/multiracial

- American Indian
- Alaska Native
- Asian
- Native Hawaiian/ Pacific Islander
- Other, please specify _____

Tell us about other medical condition(s) this child might have in addition to the cleft:

How many children younger than 18 years old live in your household: _____

How many other children with a cleft lip and/or a cleft palate do you have? _____

Are there any other people other than your child with a cleft lip and/or a cleft palate, with special health care needs living in your home? Please tell us about these people:

Our interest is learning how the recent economic downturn has affected your family and your ability to obtain medical care for your child with a cleft.

Please tell us how your family has been affected by the recent economic downturn. Have you or a household member lost your job, experienced reduced work hours, or other change:

Please tell us how your living situation has been affected by the recent economic downturn. Has your family experienced a home foreclosure, a rental eviction, or otherwise changed residence or living situations for economic reasons?

Please tell us how obtaining medical, dental or speech services has been affected by the recent economic downturn:

Please rate to what extent the **downturn of the economy** has affected your ability to access medical care for your child with a cleft:

	No change	Slight change	Moderate change	Substantial change
*Decrease or loss of income				

<ul style="list-style-type: none"> *Loss of health insurance altogether *Cost of health insurance premiums *Cost of health insurance deductibles/co-pays *Health insurance denials *Loss of Medicaid/SSI benefits *Loss of CSHCN benefits (Children with Special Health Care Needs) *Cuts to government and/or community services *Loss of flexibility relative to work hours *Loss of transportation *Cost of transportation *Change in residence for economic reasons 				
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Which of the following have been issues for you, past or present, in accessing medical care for your child with a cleft? Please rate:

	Never an issue	Almost never an issue	Sometimes an issue	Often an issue	Almost always an issue
Lack of health insurance					
Cost of health insurance premiums					
Cost of health insurance co-pays and deductibles					
Insurance denials					
Insurance stipulations (e.g., exclusions, pre-existing conditions)					
School hours/days missed by child					
Missing work for medical appointments					
Finding a doctor/team that will treat your child					
Availability of medical appointments					
Availability of transportation					
Cost of transportation					
Distance from home to medical appointments					
Overnight lodging					

Other travel expenses					
Obtaining/paying for childcare for siblings					
Meeting the needs of other family members					
Tending to other family/household responsibilities					

Please tell us about types of doctors or clinics where you get cleft-related health care for your child with a cleft lip and/or cleft palate:

Do you go to a cleft or a craniofacial team for evaluation or care for your child?

YES NO DON'T KNOW

What is your **affected child's primary** health insurance plan? This is the plan which pays the medical bills first or pays most of the medical bills.

- No health insurance
- State employee health plan
- Group health insurance plan provided by or purchased through an employer
- Employer's self-insured (self-funded) plan
- Private family/individual health insurance plan purchased directly from an insurance company or through a broker
- Medicaid
- SSI
- Children with Special Health Care Needs (CSHCN) program
- A state-specific government-sponsored program
- Military/veteran health services
- The Indian Health Services
- Do not know/not sure
- Other, please specify _____

What is your **affected child's primary** dental insurance plan?

- No dental insurance
- State employee health plan

- Group health insurance plan provided by or purchased through an employer
- Employer's self-insured (self-funded) plan
- Private family/individual health insurance plan purchased directly from an insurance company or through a broker
- Medicaid
- SSI
- Children with Special Health Care Needs (CSHCN) program
- A state-specific government-sponsored program
- Military/veteran health services
- The Indian Health Services
- Do not know/not sure
- Other, please specify _____

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