CULTURE AND CREDIBILITY: THE SENSE-MAKING PROCESS OF PERUVIAN PARENTS FOLLOWING THEIR CHILD'S CLEFT DIAGNOSIS

by

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(Under the Direction of Jeffrey K. Springston)

ABSTRACT

This study investigates the sense-making process of parents in a developing country after receiving an oral cleft diagnosis for their child. Data collection took place at an Operation Smile mission in Juliaca, Peru and consisted of timeline interviews to investigate individual sense-making processes and a survey to gauge levels of credibility assigned to health information from a variety of communication channels, both mass and interpersonal. Results showed that both culture and credibility influenced information-seeking behaviors and should be taken into consideration by health communicators. Recommendations are made for health communication practices to educate Peruvian parents and the general Peruvian public about clefts using channels and formats they are familiar with and receptive to. Implications for practitioners in other settings and Sense-making Theory are discussed, as well as study limitations and future research.

INDEX WORDS: Sense-making, Cleft lip, Cleft palate, Peru, Health communication, Parents, Operation Smile, Culture, Channel credibility, Sense-making Methodology, Timeline interviews, Developing country, Health, Mass media, Sense-making Theory

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DEDICATION

Dedicated to Dr. Karyn Jones. Who knew when I walked (or hobbled on crutches) into your classroom as an undergrad nine years ago this is where I'd end up. Thanks for being on this adventure with me.

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> "We must find time to stop and thank the people who make a difference in our lives."
>
> — John F. Kennedy

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TABLE OF CONTENTS

Page

CHAPTER

LIST OF TABLES

Page

LIST OF FIGURES

CHAPTER 1

INTRODUCTION

It is one of the most common birth defects in the world, affecting one in 700 children (Vanderas, 1987). It is entirely correctable, with follow-up services allowing individuals to lead completely normal lives. Yet receiving it as diagnosis for their child can be one of the most confusing and devastating experiences for parents in a developing country. What is it? A cleft lip and/or palate.

Having a child with a birth defect, particularly cleft lip and palate, is an emotional and stressful time for a parent. The stress is often compounded by feelings of embarrassment or shame in developing countries where strong cultural beliefs about the causes of clefts exist (Mednick et al., 2012). Receiving a cleft diagnosis instantly changes all plans parents had for welcoming and caring for their new baby. Whether diagnosed prenatally or at birth, parents are immediately sent on a quest for information to make sense of the diagnosis they just received; making the point of diagnosis and corresponding thoughts and behaviors crucial to study. Regardless of their traditional health orientation, they become active health information seekers rather than passive information consumers, changing how they interact with common entertainment and information communication channels (Dutta-Bergman, 2004). Accurate and appropriate information that answers any of the numerous questions parents have about clefts or caring for their baby is needed quickly and is sought from a number of communication channels at the same time.

Partnered with and possibly increasing their desire for information, most parents of children born with clefts have anxiety about their child’s appearance, speech, and outcomes of future surgeries (Johansson & Ringsberg, 2004). Along with the joy of welcoming a new baby, many are consumed with feelings of guilt and despair about their child’s cleft, but remain hopeful overall (Johansson & Ringsberg, 2004; Nelson, Kirk, Caress, & Glenny, 2012). Concerns about social stigma and perception arise as the child grows (Nelson et al., 2012), making the diagnosis appear to foreshadow a life of non-acceptance and judgment. These conflicting emotions add another level of motivation for quick information seeking and sense making. Not only do parents want to understand clefts so they can care for their baby, but answers will help to calm their overwhelming emotions, allowing them to make informed decisions and act in the best interest of their child.

Though a prenatal diagnosis is ideal, allowing parents to reflect on their emotions, begin information seeking, and preparing for the birth of their special needs child (Johansson & Ringsberg, 2004), it is not common in the developing world. Parents in these countries are often left with confusing and conflicting information from hospital staff after their child’s birth, rather than senses of empowerment and preparedness experienced by those that have already begun or completed part of their information-seeking and sense-making journey (Johansson & Ringsberg, 2004). The late diagnosis may also impact the care the baby receives by forcing parents to seek, collect, and process information faster. This added time pressure may influence what communication channels are selected, what information is evaluated as acceptable, and what conclusions are drawn from that information.

Significance

Before learning their child has a cleft, some parents may have heard about clefts in the media, but general knowledge about the condition is low (Johansson & Ringsberg, 2004), generating an information-seeking journey with no true orientation or guided direction. By any means possible parents strive to obtain honest and thorough information in order to adapt, adjust, and adequately prepare to care for a child with an oral cleft (Wyszynski, Perandones & Bennun, 2003). To do so they turn to a number of communication channels, both mass and interpersonal, for information. The collected information, with levels of accuracy and quality unbeknownst to the parents, is then processed and sense is made of it in a way that suits their individual needs and situation. The process as a whole, including channel selection and information evaluation, warrants academic study. Sense-making provides an often underused but valuable framework for such a venture.

The sense-making process has been studied in patients facing cancer and other medical conditions, but research is lacking on the sense-making process for caregivers of individuals within a unique health context. It is particularly absent regarding parents of children with unanticipated birth defects who face extreme emotional conflicts along with time sensitive informational needs following an unexpected diagnosis. Clearly parents of children with oral clefts are able to make sense of their child's condition in a manner that is appropriate for their life and family because by the time the child reaches pre-school age, stress levels of parents of children with clefts matched those of parents of children without clefts (Nelson et al., 2012); however, an examination of how they do so immediately following diagnosis will provide insights for future health communication practices within these populations.

The selection of a developing country as the research setting provides a study population with little-to-no knowledge of clefts, yet strong negative beliefs about and attitudes towards the condition, as noted by the Spanish translation of cleft lip to labio leporino; a label that can stigmatize those with the condition. It also adds the possible influences of cultural health practices and disparities in media access that may directly impact the emotional responses and information seeking behaviors of the parents as they carry out their sense-making journey.

While this study aims to understand the sense-making process of parents of children with clefts in Peru, it is original in that it endeavors to do so through investigating communication channels usage and the roles culture and information credibility play in influencing and directing the sense-making process. By better understanding this unique process and information-seeking behaviors of this population following a cleft diagnosis, health communicators can better reach and meet the needs of the parent population, ultimately improving the quality of care provided to the child. Research findings may also prove beneficial to health communicators working with parents of children with other birth defects that are diagnosed at birth.

CHAPTER 2

LITERATURE REVIEW

A popular topic in health communication research is uncertainty reduction. These studies often investigate informational and support channels an individual uses to gain information and support for themselves or another person in order to better understand a health topic and at times make a health behavior decision. What is missing from this literature is an understanding of the process or journey each individual takes as they collect health information from a variety of sources and process it in conjunction with the thoughts and feelings they already have in a way that makes sense to them, answers their questions, and fits their lifestyle.

Sense-making Approach

The Sense-making Approach, proposed by Brenda Dervin (1998), originated in the field of library and information sciences. It “was originally developed to assess how patients/audiences/users/clients/citizens make sense of their intersections with institutions, media, messages and situations and to apply the results in designing responsive communication/information systems” (Dervin, 2000, pp. 44). It has since been applied to various communication fields, including mass and internet communication, media studies, and medical and health communication. Sense-making is a form of programmatic research, focusing on the development of alternative approaches to the study of human information use and information systems (Savolainen, 1993). It is both a theoretic and applied approach, with its study of communication behaviors focusing on developing theoretic understanding for direct use in practice (Dervin, 1992). For purposes of clarity, the capitalized Sense-making will be used in reference to the formal theory or approach, while the lower-case presentation will be used in discussion of the process or behavior.

At its most basic level, sense making means creating an understanding of or attributing meaning to something (Kari, 1998), usually through the process of communication. Thus, the theory and corresponding methodology guide researchers through an individual’s cognitive activities while acquiring and processing information. Unique to this approach is its focus on the passage of time, specific time points, and movement between them. Its ultimate goal is to generate research that assists in the design and practice of effective communication (Dervin, 1998).

Ontology and Epistemology

When proposing the approach, Dervin (1998) set forward an original ontological and epistemological foundation. Sense making is based on both ontological and epistemological assumptions of incompleteness. Ontologically it claims that reality is incomplete because of discontinuities and changes occurring across time-space (Brendlinger, Dervin, & Foreman-Wernet, 1999; Dervin, 2008). These discontinuities or gaps must be bridged and holes in knowledge and information filled in order for individuals to move forward in their own reality. In layman’s terms, individuals are continually gathering and processing information to answer questions and guide their movement forward. This process can be either through conscious effort to gather and process information or an unconscious consumption of information partnered with movement through daily life.

Sense making is employed whenever one of these disconnections or discontinuities is reached in everyday life (Westbrook 2006). At times, the simple passage of time can fill or cover a discontinuity (Reinhard & Dervin, 2011), but in most cases an individual must use internal and external resources to make their path complete. It is notable however, that ontologically the theory does not assume people are always stopped by real gaps (Reinhard & Dervin, 2011). At times it is appropriate or necessary for a question to go unanswered or a decision to be made before adequate information is collected. So while the question remains, the individual moves forward. While there are constantly discontinuities and interruptions that arise, the magnitude of the gap and the way in which it is approached determines an individual's ability to move forward and the time and effort given to do so.

Epistemologically, expert knowledge of reality is incomplete because it is limited to a specific time-space, culture, physiology and psychological context (Brendlinger et al., 1999). The recognition of incompleteness by this theory and its methodology forces researchers to share the role of theorist with the subjects being studied. Subjects are the only true experts at a given time-space (Brendlinger et al., 1999; Spirek, Dervin, Nilan & Martin, 1999) because they have a specific knowledge and information set unique to their situation and experience. So while researchers and subjects may be able to understand reality for a short period of time, its ever changing nature means the reality will not last. It will also not be known or viewed as the same reality by another individual present at the same time.

Sense-making Theory

Sense-making Theory is based on several foundational building blocks that include: time, space, movement, gap, step-taking, situation, bridge, and outcome (Dervin, 1998). But of primary note is the "idea of the human, a mind-body-spirit living in a time-space, moving from a past, in a present, to a future, anchored in material conditions" (Dervin, 1999, pp. 730). It is this movement and the motivations behind each movement that the Sense-making Approach seeks to understand, thus making the theory heavily focused on individual cognitions.

The three main components of Sense-making Theory-- the situation, the gap, and the help/outcome (Kari, 1998) -- are often diagrammed in a triangular manner (Cheuk, 2007). Although Dervin acknowledges the depiction is highly abstract (2000), it is commonly used to explain the relationships between the basic theoretical constructs (See Figure 2.1). Sense-making Theory views information use as a continual process that provides value when individual behavior is analyzed as an entity acting in a specific time-space (Savolainen, 1993). It focuses on verbing, or the "hows" and "whys" of meaning, and sense creation and the actions used in the process (Souto, 2009).

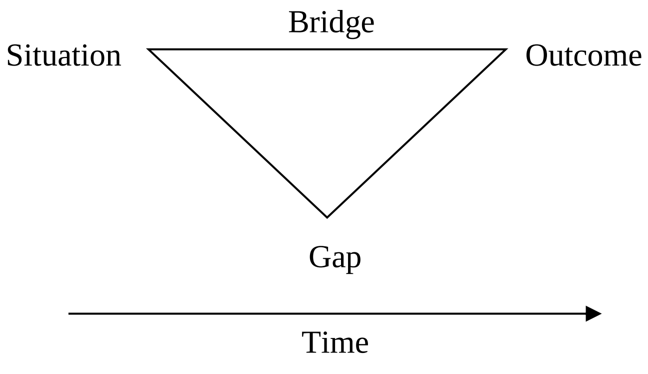

Figure 2.1. Sense-making Triangle

Verbing, an ontological category, is defined as the creation of emotional and cognitive elements that serve in the acts of sense making and sense unmaking (Savolainen, 2006). The verbs that communicate behavior in the sense-making process revolve around information seeking, processing, creating, and using (Savolainen, 1993). Individuals can choose a wide array of verbs to use when traveling along their sense-making path and their movement can be classified into three groups. According to Nilan and Dervin (1999), these include: “problematic,” or forced down one path, “decision,” or free choice between two paths, and “led,” or guided down a path freely chosen by an individual. Each verb is a different type of bridge used to cross a gap and the information sought to build the bridge depends on how an individual evaluates what type of gap they are facing (Savolainen, 2006). Common categories of verbs found in sense-making research include: defining, doing, connecting, removing, projecting, and motivating (Nilan & Dervin, 1999).

Of the theory’s three core concepts, the gap is where most attention is paid by researchers. The gap is where questions arise and knowledge and information is missing. It is where sense-making actions as well as communication can be found (Dervin, 1998). The manner in which an individual approaches a gap is important to understand because no two people will approach a gap in the same way. Even if it is in the same context, such as having a child with a cleft, individuals will have different perceptions of, emotional reactions to, and current knowledge of the situation. This leads to different gaps, questions, and informational needs for each person. It also motivates different methods of information seeking to fill the gap.

There is an intertwined connection between how an individual looks at a situation and gap, and the sense they are about to make of it (Dervin, 1998). Due to personal differences, each person will perceive the size of the gap and the usefulness of possible helps differently (Savolainen, 2006), although research aims to find patterns in perceptions and behaviors with in a population in order to improve communication practices. Additional emphasis on the gap, as well as verbing, can be seen in Dervin's recent depiction of the Sense-making Approach (See Figure 2).

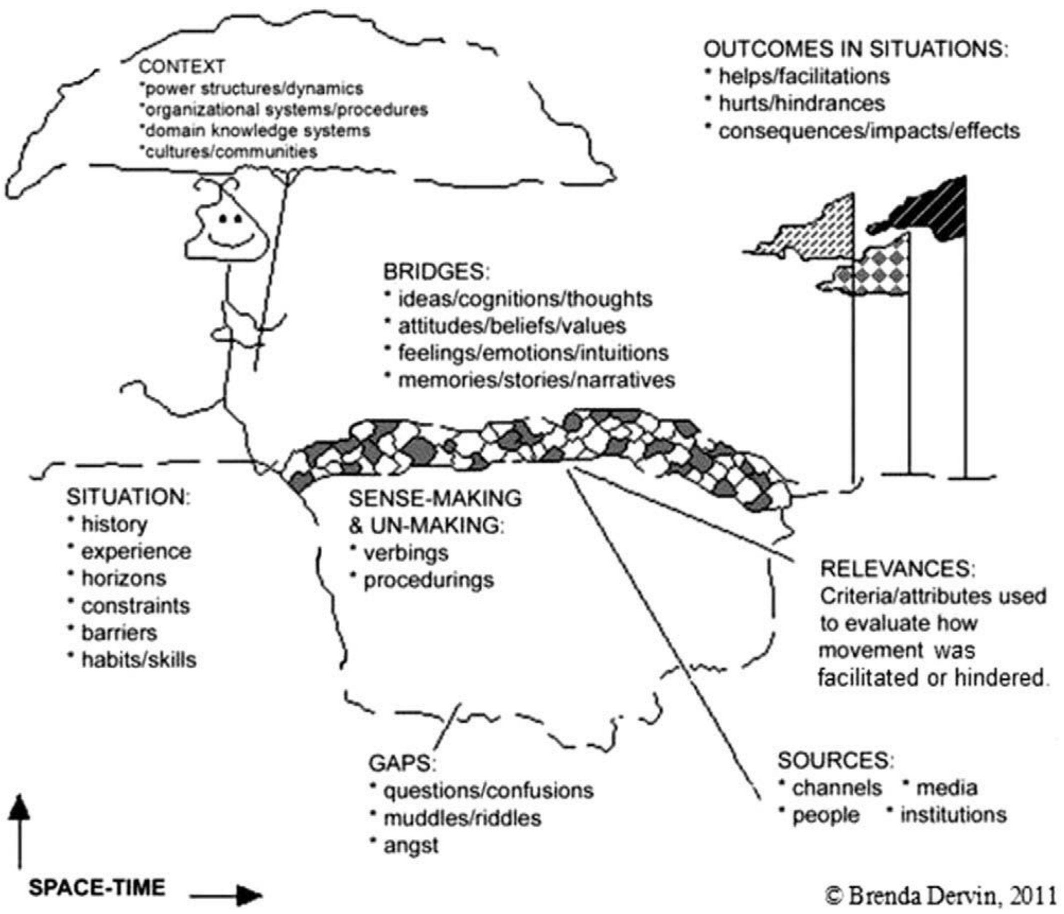

Figure 2.2. Dervin's Sense-making Approach (Reinhard & Dervin, 2011)

While evaluating how information collected or a help will be useful in crossing a gap, there is a distinct line between planning to bridge a gap and actually bridging it (Savolainen, 2006). Bridging a gap can happen in phases or all at once. It consists of locating, identifying and blending ideas, beliefs and narratives (Savolainen, 2006). Gaps, however, are not always bridged and that is not always a negative. For example, deciding not to give out private information to gain access to a website that may contain valuable information halts any forward movement over a gap (Nycyk, 2010) and forces an individual to redirect their behavior and or goals.

A criticism of the situation-gap-help model is that the perceptions of information success or failure that create an individual's reality are constructed uniquely by that individual, making all observed hindrances subjective (Nycyk, 2010). It is this subjectivity that when applied to a perceived problem motivates some people to seek meaning in some situations and others to take no action at all (Solomon, 1997). Subjectivity, however, is widely acknowledged in the field of sense making, particularly in assessment of gaps (Savolainen, 2006). Because of the subjective nature of the sense-making process, innocent information, or information that is objective, value free, yet socially constructed (Martin, 2010), is difficult to obtain. While it can affect the ability to generalize results outside of the studied population, it is often not seen as a limitation to research. In fact, the Sense-making Approach values "the uniqueness of individuals and their circumstances, while identifying commonalities in the processes they go through. Such commonalities permit systems and services to be created that provide appropriate help" (Morris, 1994, pp. 22).

Knowledge and Information

The debate between what is considered knowledge and what is considered information is ongoing. While it is important that both are understood, even more relevant is their role in sense making. There is a division among researchers on whether studies should examine knowledge or information. Sense making, however, is not impeded by this divide (Savolainen, 2006) because both are used together in the sense-making process to build bridges and cross gaps. The actions taken to find, create, blend, and use knowledge and information are the core of the approach and the focus of sense-making research.

Knowledge plays an important role in sense making, but it is often operationalized differently by researchers. Definitions usually fall within the realm of an already possessed and internal set of ideas and opinions. Knowledge should never be seen as a truth because it will be challenged over time as new information emerges (Cheuk, 2007). Traditionally, communication research has focused on the creation of knowledge as a product and not a process, when in fact the knowledge creation process is a form of sense making (Souto, 2009). This process provides a foundation or starting point for future sense-making processes when new gaps are reached.

Information is commonly operationalized as ideas and facts obtained from an outside source. Accrual may be through purposeful research, mass media consumption, or interpersonal interactions. While it is an important part of the process, sense making does not support the notion that information attainment is an end point. It is merely a way to reach an end point (Dervin, 1998). Sense making demands the elimination of the term information as a static and absolute ontological category (Savolainen, 2006). Instead it recognizes that information will constantly be evaluated and processed with an individual’s current knowledge, leading to different interpretations that can depend on an individual’s situation and the manner in which he or she approaches gaps.

The study of human information behaviors in the sense-making process allows for the discovery of individual strategies, expectations, attitudes, and anxieties (Solomon, 1997). This process, however, rarely follows a linear path (Savolainen, 2006). Resource selection, information gathering and processing, and decision making can happen in any order and steps can overlap or be repeated multiple times before an acceptable end point is reached and a bridge is built to cross a gap. Additionally, although the situation is different due to the passage of time, occasionally individuals may resort to answers or steps that helped them bridge similar gaps in the past (Savolainen, 2006), thus eliminating the need for new information-seeking behaviors. These instances are rare, however, because knowledge made one day is rarely suitable for the next (Dervin, 1998).

Through the sense-making process, information obtained, once processed and sense made of it, becomes knowledge or the product of the sense-making process (Savolainen, 1993). It then combines with an individual’s current knowledge, creating another round of new knowledge that shapes an individual’s mental concept of an issue that then influences attitudes and behaviors. Notable however, is the flexibility of these concepts to change as one moves through time and space.

Time

Time is another crucial component of sense making. Whether it be a long or short period, the notion that sense making takes time is often an oversight and researchers must be reminded that it should be considered a vital factor in any study (Solomon, 1997). The amount of time taken to make sense can be a factor in analysis and must be acknowledged. This constraint is demonstrated in the processes and outcomes mentioned earlier of parents who received a cleft diagnosis prenatally and thus had time to make sense of it before their child's birth compared to those who did not.

Time may also interact with other variables in the sense-making process, such as credibility of communication channel, and increase or decrease its influence, depending on how quick a decision needs to be made or action needs to be taken. As demonstrated by Dervin, Nilan, and Jacobson (1981) in their work with blood donation centers, each step of the donation process came with its own set of questions and informational needs that were not being met at appropriate times. By adjusting the time points at which information was distributed, the center was better able to inform and maintain donors. Finally, time can impact the effectiveness of an information bridge in crossing a gap because as information is searched for, time is passing and the gap is changing (Dervin, 1999). Therefore, the bridge built may address the gap of one day, but be slightly misguided for the shape or depth of the gap the next day.

Power

Although not one of the components of the sense-making triangle, power is another important influence to consider in the sense-making process (Dervin, 2008). It pervades all human conditions and can be perceived as a barrier, constraint, facilitator, or motivator (Dervin, 1999). There is a long-standing need in society and research for "right" answers, but as demonstrated by sense making, forces of power in society that prescribe answers are hindrances to the individual sense-making process (Dervin, 1998). Power can stem from personal, institutional, or societal sources. It should be studied to understand what facilitates (Dervin, 2000), hinders or constrains movement (Cardillo, 1999).

While individuals can be controlled and influenced by hegemony, they also have the internal power to create, transform and resist social forces (Dworken, Foreman-Wernet, & Dervin, 1999). Individuals can free themselves from cultural, historical and institutional restraints (Cardillo, 1999) and use their own power to challenge that of others (Dervin, 1999). When appropriate, addressing structural power arrangements can provide strong insight into the sense-making process (Nilan & Dervin, 1999). Influences and attributions of power to a given source may also explain variance in credibility and trust that influence the sense-making process from another angle.

Sense Making and Health

Studying sense making in health contexts is more important now than ever before. Due to advancements in the medical technology and services fields, health behavior decisions will soon have more to do with values than science (Martin, 2011). And while extremely beneficial in improving health and quality of life, these progressions and advancements in science and medicine can create as many gaps as they fill (Martin, 2011). While information can answer one question, it will often create another. This may prove particularly true among non-health literate populations that do not fully understand the information they receive. Sense making is also useful in demonstrating that patients and practitioners look at disease differently (Nelissen, van Eden, & Maas, 1999). The recognition of different views assists in improving communication practices between the two parties as they both experience sense-making processes of a given disease. An example of this being the sense-making research done at a cancer center with both patients and staff that found that staff could better meet the informational needs of patients by using sense-making questions when interacting with them, but in return they needed communication outlets to let them connect with patients outside the disease to make the sadness of their daily jobs more manageable (Dervin & Frenette, 2000).

In health settings, issues of power and control often dominate. These struggles are particularly prevalent in communication research with children and adolescents (Cardillo, 1999). When the foundations of sense making are applied to power conflicts in health settings, the assumption that a doctor's expertise should prevail is challenged and put in communion and contest with a patient's knowledge of his or her body (Cardillo, 1999). Noncompliance may be proven as a rational and responsible action when analyzed with a sense-making lens (Cardillo, 1999).

An example of such behavior can be seen in research by Heldal and Tjora (2009) that describes a patient, who after researching his health condition, decided to go against his doctor's treatment advice and seek alternative care outside of his home country. In this case, the sense-making process allowed the patient to take control of his own care and select a treatment path that made sense to him and his situation despite medical expert recommendations. It also forced the medical staff to make sense of the uncommon and rebellious behavior. For these reasons, sense making in health communication demands not only evaluating information seeking and knowledge creation, but delving into an individual's narrative of lived experience while attending to how they constitute and are constrained by cultural forces (Cardillo, 1999).

Acquiring information to process with current knowledge in a situation is crucial for patients and families to make decisions regarding care seeking or situational coping.

Recently diagnosed patients have been found to seek information from a variety of sources, both professional and lay. Information seeking can be deliberate or serendipitous (Dutta-Bergman, 2004), and at times can include simply comparing oneself to others in similar situations. No matter what method of information seeking is employed, all individuals try to fill gaps and make sense of their new condition, continually reframing and reinterpreting their situation (McCaughan & McKenna, 2007).

As demonstrated by Feltwell and Ress (2004), information can reduce uncertainty and anxiety. Additionally, Galloway et al. found information can facilitate coping, while Fernsler and Cannon demonstrated it can enhance self-care abilities (as cited in McCaughan & McKenna, 2007). Making sense of a complex situation often requires an individual to turn to alternative sources of information they may not have utilized before (Nycyk, 2010) or not previously considered to be helpful in a health context. This is especially clear in the emergence of several mass communication channels as health communication channels and their utility in the sense-making process.

With the understanding that health can be a strong motivator for information seeking and sense making, the central research question for this study is posed,

RQ1. At the point of receiving a cleft diagnosis for their child, how do parents in developing countries make sense of it?

Sense Making and Media

The media, whether it is television, radio, newspaper, magazine, etc., is a common form of health communication and is often used by individuals seeking to gather information on a specific health topic. While able to provide insight, factors used in media studies can fail to provide predictive value. This makes behavior look chaotic, when in fact outcomes are the result of audiences not being studied in a life-as-it-is-lived manner (Spirek et al., 1999). Once the sense-making process is understood, these behaviors may be seen as rational, orderly, and well thought out.

In the information seeking and sense-making process, individuals encounter media reception situations, or specific sequences of time-space movements within which the person engages through interconnected performative and interpretive actions and reactions with content or messages via a media technology (Reinhard & Dervin, 2011). This information is then evaluated using prior knowledge, the information is accepted or rejected based on the specific situation, and the sense-making process continues. Because of this continual, intentional, and important media use, there is a need to study the similarities and differences of people engaging with different media products and channels (Reinhard & Dervin, 2011) and how each aids in the sense-making process. Evaluating channel use is a popular way to quantitatively study media audiences (Spirek et al., 1999), understand what channels individuals turn to in the sense-making process and why they do so.

Sense making has been used to study alternative and non-mainstream forms of mass media like radio programming directed at mine workers in small towns to show the value of studying communication-as-procedure to understand differences with main stream media (Huesca, 1999), public access television’s ability to increase media literacy and self-awareness among participating producers (Higgins, 1999), and motivations behind postings in electronic discussion groups, even when they proved to be a non-dialogic form of communication (Schaefer, 1999). It has also been used to compare the sense-making process of living an experience versus receiving information about it from a mainstream media, such as a newspaper (Spirek et al., 1999). Many sense-making studies involving some type of media led to the subjects developing feelings of empowerment or a sense of community relating to their situation.

Other work, while not directly examining media content, used Sense-making Theory to understand how health campaign messages in the media should be framed in order to reach the informational needs of a target audience. Using a sense-making survey, it was discovered that the questions individuals in a studied community had about HIV/AIDs did not match how the health department traditionally-framed messages. Those in the target audience were rather knowledgeable about the disease, but wanted more information about how it would affect their life and the lives of their loved ones and less information on the technical or medical side (Brendlinger et al., 1999). The health department was able to use this information to then design communication messages for their campaign that would be effective within the target audience.

What is missing in the literature is research on utilizing multiple communication channels in the sense-making process. There is a lack of knowledge regarding how multiple communication channels are utilized simultaneously to fill a single gap in the sense-making process. There is no current literature on how individuals make sense of a single health condition using multiple communication channels and what characteristics of the audience or each channel make it perceived as a reliable health communication resource.

With time pressures to makes sense of a cleft diagnosis fast and potential disparities in access to various communication channels, the second research question for this research study is posed, with hypothesis put forward based on knowledge of the research setting.

RQ2. Upon diagnosis, what communication channels do parents of children born with clefts in Peru use to gather information to help make sense of their child's condition?

RQ2a. Which channels are found to be most informative and easiest to understand by the target population?

H1. Due to potential disparities in access to mass media channels and the internet in developing countries, interpersonal communication channels, both lay and expert, will be used most by parents to obtain information about their child's condition.

H2. Because they are predicted to be used most often, medical professionals and friends and family will be found to be the most informative and easiest to understand channels when looking for information on clefts.

Sense Making and Credibility

Although not commonly evaluated in sense-making studies, attributed credibility of information from a communication channel can be influential in an individual's sense-making process. What one person deems a credible channel from which to receive health information and thus deserving further thought or investigation may be labeled as insignificant or unhelpful by another, even if both are trying to bridge a similar gap. During the sense-making process, individuals search for information to make sense of in order to build their own individual bridge, making it important to understand what factors influence channel selection for information retrieval. It is this attitude toward a specific communicator or method of communication that is crucial but rarely studied (Hovland & Weiss, 1951).

First and foremost, in any study relating to notions of credibility, the term must be operationalized and that definition must be carried throughout a study in order for results to be legitimized (McCroskey & Young, 1981). Currently there is no agreed upon definition for credibility (Meyer, 1988) and the variety of definitions used have been a main source of conflicting results in the field (Trumbo & McComas, 2003). Credibility is often divided into two subcategories: channel credibility and source credibility, each with their own set of constructs.

Channel credibility is associated with an audience’s perceptions of a given communication channel and the information it provides. Its easiest assessment comes from asking respondents whether information from a channel is believable (Wathen & Burkell, 2002). It is often influenced by demographics (Kiousis, 2001; Johnson & Kaye, 1998). From a sense-making perspective this is seen in work by Dworken, Foreman-Wernet, and Dervin (1999) that demonstrates how perceived credibility of various modes of news coverage altered greatly when analyzed by social class. Channel credibility can also be influenced by usage rates (Johnson & Kaye, 1998) and interpersonal discussion (Kiousis, 2001). Conversely, attributed credibility may help explain usage rates (Meyer, 1988). Technical quality of communication channels also directly impacts perceived credibility (Kiousis, 2001).

Source credibility is an attribute assigned to the specific message sender, regardless of the channel used. It has been evaluated in many ways, with most analyzes concluding that combined levels of attributed expertise and trustworthiness impact source credibility (Pornpitakpan, 2004). McCroskey's (1966) popular source credibility scales evaluate authoritativeness and character to reach an overall credibility score. Berlo, Lemert, and Mertz (1969) used qualification, safety, and competence scales to evaluate source credibility. With the evolution of the field came investigation into a source's intention toward the receiver (McCroskey & Young, 1981), levels of bias (Meyer, 1988), and how each deals with audience privacy and monetary incentives (Gaziano & McGrath, 1986). Many of the factors popular in evaluating source credibility are also used to understand channel credibility.

While source and channel credibility are often divided and analyzed as separate factors influencing behavior, they have several things in common. First, both sources and channels are judged on their appropriateness of delivering certain types of information, a decision that greatly impacts credibility (Hovland & Weiss, 1951). Additionally, factors used to evaluate both can be influenced by the passage of time (Hovland & Weiss, 1951), location of source (Gaziano & McGrath, 1986), and the effects of primacy and recency (Crano, 1977), making one or both appropriate to include in a sense-making study.

Also similar across studies of both types of credibility is the concept of trust. Audiences assign different levels of trust to sources and channels for every message received. While there are different types of trust, including social and interpersonal (Trumbo & McComas, 2003), the general term "trustworthy" is often used as one of many constructs in credibility measurement scales. Some studies include it in a combined credibility index during analysis, while others analyze it as a separate factor. This practice is appropriate as long as the term is clearly operationalized and does not overlap with other factors being studied.

The measurement of credibility has evolved over the years, with researchers now using a myriad of methods. Semantic differential scales first came into use in 1961with Andersen to measure ethos, then were expanded upon that same year by Berlo, Lemert, and Mertz to include measures for competence, trust, and dynamism (McCroskey & Young, 1981). McCroskey then developed Likert type scales for authoritativeness and character, providing measures with high internal reliability (McCroskey & Young, 1981). The constructs used by early researchers have since been edited, reorganized and added to by others to create several renditions of credibility measurement scales and indexes (Gaziano & McGrath, 1986; Meyer, 1988). This has allowed factor analysis to become a useful method for analysis. With studies regularly using new combinations of credibility constructs and methods varying from surveys of convenience samples to controlled experiments, it is key to remember that the methods selected for both data collection and analysis will directly influence the results and conclusions that can be drawn (Johnson & Kaye, 1998).

In recognition that a factor like channel credibility can influence an individual's channel selection for health information seeking purpose and the sense-making process, the third research question is asked.

RQ3. What levels of credibility do parents assign mass media and interpersonal communication channels as sources of general health information?

H3. Because they are hypothesized to be the most used by parents, health information from friends and family and medical professionals will be assigned higher levels of credibility than the other studied channels.

H4. Relatively equal levels of credibility will be assigned to all mass media communication channels (television, radio, newspaper) as sources of health communication.

Sense Making and Culture

While it is not directly acknowledged in many sense-making studies, health communication research demonstrates that culture can and does play a strong role in the sense-making process; however, individuals are not bound by it and can consciously act to free themselves from its restraints (Cardillo, 1999). Culture has the ability to influence health beliefs and information-seeking behaviors, both important aspects of the sense-making process. This influence may permanently ingrain certain ideas or actions into traditional culture. "It is generally believed that by understanding the cultural characteristics of a given group, public health and health communication programs and services can be customized to better meet the needs of its members" (Kreuter & McClure, 2004, pp. 439). It is important to recognize the influence of culture to help reduce difficulties encountered by professionals when trying to work with a population that is distanced from mainstream culture (Maher, 1999).

The most prominent influence of culture in the field of sense making is the impact it has on commonly held health beliefs, or the starting point of the sense-making process. These beliefs and attitudes play a central role in how populations approach their own health and the use of resources (Applewhite, 1995), as well as how they perceive and approach a gap. In the case of oral clefts, there are several culturally held beliefs on why clefts occur. In many developing countries, supernatural powers are believed to be the cause of clefts and the baby is seen as a curse on the family or punishment for their past sins (Mednick et al., 2012). Hutchinson et al. concludes that due to these strong cultural beliefs, families rely less on medical explanations of clefts and more on folklore or religion (as cited in Mednick et al., 2012). Without full attention paid to cultural beliefs, full benefits of any repair or treatment may not be realized (Mednick et al., 2012). By understanding an individual's view point, congruency of meaning can be achieved (Maher, 1999) between individuals and health communication practitioners.

Culture also has the ability to influence channel selection in audience segments. Each medium has unique attributes that attract certain audiences. Whether it is sensory appeal or level of interactivity, the recognition of channel characteristics that appeal to different cultures can lead to more informed decisions on which to use in health communication efforts (Kreuter & McClure, 2004). In some populations, culture may turn individuals away from the mass media all together. In cultures that strongly value family connections, lay sources of information have been found to be the most popular ways to gather health information, with individuals reflecting on their personal experiences and those of their family and friends (Greenhalgh, Helman, & Chowdhury, 1998).

Even without the term "sense making" being used, the influence of culture on beliefs and behaviors is acknowledged in the strategies and approaches taken by health communication programmers. Language is an important part of a culture and linguistic strategies have been used by health communication practitioners to make materials more accessible to their target audience (Kreuter & McClure, 2004). Effective use of a local dialect, indigenous language or terminology familiar to an audience can potentially influence channel selection and message acceptance. "Sociocultural approaches present health messages in the context of social and/or cultural characteristics of the intended audience," allowing their values, beliefs, and behaviors to be acknowledged and built upon (Kreuter & McClure, 2004, pp.446). By molding health messages to a specific culture and showing audiences how content is applicable to their lifestyle, message reception and acceptance can be increased even if information conflicts with commonly held beliefs.

With this knowledge, the final research question is posed.

RQ4. What influence does culture have on the sense-making process of parents after receiving a cleft diagnosis for their child?

CHAPTER 3

METHODS

Sense-making Methodology

Accompanying Sense-making Theory is Sense-making Methodology, a specific research approach designed to uncover the sense-making process of an individual. Sense-making Methodology is a methodological technique and a conceptual approach to understand meaning making through information interaction (Westbrook, 2006). It is intentionally multi-dialectical (Dervin, 2008). The methodology focuses on the same core tenants as the theory: movement through time and evaluation of verbs and not nouns. Unique from other communication research methodologies, Sense-making Theory does not focus on the individual receiver or message content for analysis. Instead, the sense-making instance is the unit of analysis and results are applied to this instance and not the individual (Dervin, 1998). Because individuals are not the unit of analysis, their conceptualization of moment through time and space is more important than demographics in predicting sense making (Dervin, 1998).

This specific methodological approach meets the recent call for a more culturally and experientially sensitive audience-oriented research practice, particularly in health communication contexts (Brendlinger et al., 1999). Included methodologies are unique in that they operate in both an inductive and deductive manner (Higgins, 1999). “Sense-Making stands between approaches (usually the more quantitative) which too often relegate the term methodology to method; and approaches (usually the more qualitative) which too often elide the term methodology into meta-theory” (Dervin & Clark, 1999). Because of this middle ground, several data collection methods can be used to study the sense-making process. Interviews and surveys are the most common and have proven most effective. These methodologies often focus on the most popular sense-making dimensions: past experience, expectations, questions, helps, and hindrances (Reinhard & Dervin, 2011).

Because Sense-making Methodology requires specific research designs, special acknowledgements must be made in the analysis stage of research. Crucial to analyzing results collected through sense-making methodologies is the notion that categories of responses are not to understand reality, but rather to understand the respondent on their own terms (Cheuk & Dervin, 1999). This again highlights the subjective nature of the field. Generalizing results from sense-making studies can be difficult, but not impossible. Because situations for individuals can be similar but not identical, all generalizations and recommendations made must be done within a defined population rather than a mass audience (Johansson & Ringsberg, 2004).

Timeline interviews. Interviews used in sense making are designed to be used with both qualitative and quantitative analysis methods and are used as an approach to elicit and hear what people want, think, need, feel, experience, and struggle with (Dervin, 2008). Micro-moment timeline interviews or timeline interviews are a popular methodology in sense making. Like other sense-making methods, the sense-making instance or moment in time is the unit of analysis (Cheuk & Dervin, 1999). By looking at the sense-making process across a time span, micro-level details that are often lost can be uncovered, allowing all sense-making activities to be seen (Solomon, 1997).

Conducting timeline interviews under the Sense-making Methodology requires following a specific protocol. Time-line interviews are comprised of three basic steps. First, interviewees are asked to narrate step by step what happened in a given situation at a specific time point. Then, each step is analyzed further with probes asking specifically about gaps, questions, and blocks encountered at each. Finally, targeted questions are used to uncover how gaps and blocks were approached, perceived and later evaluated (Savolainen, 1993). While questions are planned ahead of time, interviews must be somewhat unstructured to allow for focus on the verbing that leads to sense being made (Higgins, 1999). The interviewer only says enough to focus the interview on the desired situation of study and the respondent names their situation, gaps, helps, hurts, questions, confusions, conclusions, feelings, emotions, ideas, and understandings (Cardillo, 1999). The interviewer's main goal is to listen, while the participant drives the conversation. Probing is commonly used to highlight or elaborate on actions and interactions, but not guide answers.

The methodology is designed so that probe and follow-up questions do not interrupt the subject's narrative, but still allow researchers to dig beyond the surface (Reinhard & Dervin, 2011). This reflective thinking by the respondent is a cognitive activity and continuous process that can be conceptualized as building and expanding on past and current experiences for the benefit of better situational understanding (Teekman, 1999). For participants currently experiencing the situation being analyzed, this manner of thinking has helped them evaluate a situation and their role in it, as well as act in an intelligent manner (Teekman, 1999).

Surveys. Surveys have been a primary tool for conducting audience research. In traditional form, however, they are not appropriate for evaluating the sense-making process. Therefore a call was made for more transactional survey research (Brendlinger et al., 1999). Brendlinger, Dervin, and Foreman-Wernet (1999) describe the work done by Sobo, Zimet, Zimmerman, and Cecil (1997) and Warick, Aggleton, and Homans (1988) that found surveys to show how acquainted an audience is with a media, but not their internal interpretive frameworks. Results of these surveys often lead researchers to believe behavior is uninformed, when in fact, as Pinkerton and Abramson (1992) found, when the sense-making process is studied, the same behavior is seen as rational and any risk taking judged to be worthwhile.

Surveys used in Sense-making Methodology invite respondents to develop their own constructs, draw connections among those constructs and talk freely about successes and failures (Brendlinger et al., 1999). Although collected as a traditional part of survey research, in sense making, the assessment of blockages of movement explain more variance in behavior than demographics (Nilan & Dervin, 1999). Surveys can thus be useful to gather information on a particular potential blockage or bridge-building aid in the sense-making process that can be addressed or improved once understood.

Current Study

The moment of diagnosis, particularly for one’s child, is a moment of entering an unknown territory. At this point it is almost impossible to fully understand the situation and endless number of gaps that are created for each parent. Therefore sense making is impeded at a time when it is needed most (Nelissen et al., 1999). This transition in situation makes the point of diagnosis a crucial moment in time-space to study with

Sense-making Methodology because a parent must quickly bridge any gaps that arise in order to best care for their child.

In the current study, the situation is having a child diagnosed with a cleft. The gap is the absence of knowledge and information about the condition and skills to care for the child. The help or bridge is the outcome of the sense-making process (Kari, 1998), or the processed information and knowledge that allows a parent to make sense of the situation, accept it on their own terms, and care for their child appropriately.

The current study implements both time-line interviews and a survey to understand the sense-making process of parents upon learning their child has a cleft lip and/or palate, particularly the health communication channels utilized. It also evaluates how credibility assigned to health information from various communication channels may influence, help, or inhibit the sense making or channel selection process. Although asking a participant to retrospectively describe a situation can lead to recall bias, Johansson and Rinsberg (2004) justify the use of the method by explicating on previous research findings showing that using major life events, such as having a child with a birth defect, is a big enough event that it can be easily remembered.

Data collection for the interview and survey components took place at an Operation Smile mission in Juliaca, Peru in November 2012 with parents who chose to bring their child to receive surgery. Both the survey administration and the interview process were carried out with the assistance of Spanish-speaking translators from Peru.

Operation Smile is “an international medical humanitarian organization dedicated to raising awareness of this life-threatening issue [cleft lip and palate] and providing lasting solutions that will allow children to be healed, regardless of financial standing”

(Operation Smile, n.d.). Founded in 1982, Operation Smile provided cleft lip and palate surgeries for over 134,520 children in its first 25 years (Bermudez, Carter, Magee, Sherman, & Ayala, 2010); a number that has since been far exceeded. In addition to surgery, the organization and its volunteers provide education, training and equipment for medical professionals in partner countries to ensure continued quality care once the mission team departs. Because of its quality reputation, presence in more than 60 countries around the world, and the researcher's familiarity with it, Operation Smile was chosen as the organization to work with.

Interviews. The time-line interview approach was selected for use because only by focusing on specific moments of sense-making practice can a respondent fully share stories, successes and struggles (Brendlinger et al., 1999). Research has demonstrated that communication in sense making works best when speakers anchor themselves in their histories and frameworks (Dervin, 1998). While there are several other important moments in time associated with having a child with a cleft, this study focuses solely on the initial discovery and diagnosis of the cleft lip and/or palate.

Seventeen face-to-face interviews were conducted with mothers and fathers of children who received surgery at the Operation Smile mission. Parents of children who receive surgery were recruited to participate because they are the ones that received the cleft diagnosis and are responsible for caring for the child. After their child received surgery, the parents spent the night in the hospital. It was at this point, when their child was recovering, that they were asked to participate. During recruitment it was made clear that the decision to participate or not would in no way impact the care their child would receive at the present time or during any follow-up visits.

Interviews were conducted in a quiet room with the assistance of a Spanish-speaking translator. While the lead researcher guided the interviews, the translator was made familiar with the study objectives and interview questions prior to beginning, allowing the translation process and clarification of any participant questions to flow smoothly. All participants signed a consent form (See Appendix A and Appendix B) prior to beginning the interview. Interviews ranged from 15 to 25 minutes.

Interview questions were based on the traditional roster of Sense-making Methodology interview questions (Dervin, 2008). Following the three steps of timeline interviews previously discussed, participants were asked to first describe when they first found out their child had a cleft lip and/or palate (See Appendix C). They were then probed on how they felt and what questions, concerns, and struggles they had. Responses set up the situation and initials gaps, as well as how emotionally and cognitively each person approached and perceived the gaps.

Next, interviewees were asked specifically what type of information they wanted about clefts and where they went to get it. For each informational source, parents were asked why they went to that source, what information they received, what they found to be helpful and unhelpful, if there were any barriers in getting information from the source, what information they felt was missing, how they felt after the interaction with that communication channel, and what new questions arose as a result of the interaction. These questions were repeated for each communication channel mentioned by the interviewee.

By the end of the interview, a complete timeline of the initial sense-making process was described through the interviewee's narrative. Gaps and bridges were uncovered, as well as specific verbs used during the sense-making process.

All interviews were then transcribed and a pseudonym assigned to each parent. Transcripts were coded to evaluate the initial questions and emotions of each parent to establish the situation and initial gaps. Further coding was then done by communication channel to understand the type information obtained, consequential new questions and emotions, and parental perceptions of missing information, ease of use, and helpfulness of each channel used.

Survey. Quantitative measures were selected for this phase of research due to their ability to explain and predict behavior based on a given variable (Cooper et al., 1994). Results are complementary to the qualitative interview phase of the study. In understanding communication channel selection, a quantitative description of current behavior and perceptions is most appropriate and beneficial (Cooper et al., 1994). When analyzed with a sense-making lens, survey results allow for the redesign and reconceptualization of the channels being studied within a specific context (Spirek, et al., 1999).

For the survey, all parents that brought their child to the Operation Smile mission were recruited. Parents were the desired sample because they are the ones that experienced the sense-making process and are responsible for the care of and health decision making for their child. It was made clear to all parents that participation in the study would in no way impact their child's chances of being selected for surgery at the present time or in the future. Because the Juliaca mission was a small local mission, patient/parent turnout was lower than anticipated, resulting in fewer completed surveys than anticipated (*N*=45). Each respondent signed a consent form before completing his or her survey (See Appendix D and Appendix E).

The survey was designed to collect data on both communication channel usage and usefulness for collecting health information on clefts, as well as levels of perceived credibility of health information from each channel to evaluate its potential role in channel selection. The survey itself was comprised of three individual sections, each with a different type of data being collected (See Appendix F and Appendix G). Order of the questions was carefully considered as it is known to impact results (Presser et al., 2004).

The first section of questions addresses media usage of each respondent. Respondents were asked to check on a list of options what communication channels they used to collect information about clefts and care for their child. The following questions ask respondents to pick one of the channels they used as the most useful and one as the least useful in collecting information; as well as which used channel provided the easiest and most difficult information to understand. For all questions, television, radio, the internet, newspapers, friends and family, and health professionals were options. Additionally, “I don’t know” and “Other” with a space to fill in what other channels was used were listed as options. The communication channels for study were chosen not only for their wide spread availability in developing nations, but for the differences in preference and usage that can be seen based on demographics and other population traits (Johnson & Kaye, 1998). While friends and family and health professionals may be seen as sources more than channels, their categorization as lay and expert interpersonal communication channels validate their use in this study.

The second set of questions aimed to address the assigned channel credibility of television, radio, internet, newspapers, layman, and experts as communicators of health information. Channel credibility was chosen for study over source credibility due to the stronger perceived influence on culture and the notion that assessment of channel credibility comes before that of a source. A parent must first decide to use a channel for health information-gathering purposes before individual sources within that channel can or need to be evaluated.

Respondents were asked to complete a set of credibility scales, one for health information from each of the communication channels. The scale sets were comprised of five five-point Likert type scales asking respondents to rate how accurate, believable, trustworthy, informative, and convincing health information in general from each channel is. The scale uses constructs previously tested and validated as a believability scale by Hallahan (1999), although his testing of the constructs utilized semantic differential scales. Responses ranged from 0=Strongly disagree to 5=Strongly agree. Of note is the inclusion of trust in the scale as a construct. Although the field of study usually refers to the perceptions of trust and credibility, most scales evaluate trust as a component of credibility, or in Hallahan's case, believability.

The Likert type format was selected for ease of understanding and completion in low literacy populations, although it is also common for semantic differential scales to be used in credibility research (McCroskey & Young, 1981). To avoid confusion, the researcher decided not to reverse code any items.

Finally, demographic questions were asked at the end of the survey. Information on age, gender, education, and family history of clefts was collected.

The language used in the survey was kept as basic as possible to assist those with low-literacy levels, a group that makes up 19.7% of the rural Peruvian population (Zeta de Pozo, 2009). The researcher was available to answer all questions during data collection; however, the survey was administered by a native Spanish speaker due to the influences of researcher characteristics and researcher-participant interactions on participation (Groves, Cialdini, & Couper, 1992), as well as the observed low-literacy levels in the respondents.

Paper and pencil administration was selected due to the onsite nature of data collection and ease of collecting answers from multiple respondents at one time. It also eliminated any difficulty respondents unfamiliar with advance technologies like iPads or computers may have faced in completing a survey using one. The elimination of these barriers was crucial because research shows that the method of administration can impact the responses given (Fricker, Galesic, Tourangeau, & Yan, 2005).

CHAPTER 4

INTERVIEW RESULTS

In efforts to answer RQ1 and understand the sense-making process parents go through once receiving a cleft diagnosis for their child, 17 face-to-face interviews were conducted with parents of children receiving cleft surgery at the November 2012 Operation Smile mission in Juliaca, Peru. Ten interviewees were mothers of a child with a cleft and seven were fathers. All interviews were conducted in private and semi-private areas to promote openness and honesty in responses. In the responses given, RQ2 and RQ4 were also answered, and clear trends in health communication channel selection and cultural influences were found.

The Situation

To begin to understand the sense-making process undertaken by these parents, the sense-making situation must first be defined. For purposes of this study, the situation and unit of analysis is the cleft diagnosis and the following information seeking period. The situation and resulting sense-making process being studied began the moment that the parent was told their child had or would have a cleft lip. For 16 of the 17 parents this situation occurred at birth. For the one that received a prenatal diagnosis, their situation was established then.

Upon receiving the cleft diagnosis the parents immediately experienced an array of emotions and had questions they wanted answers to quickly. Emotions varied drastically from parent to parent. Most parents classified their emotions as sad or scared

(Carmen, Susana, Juan, Tomas, Raul, Miguel). The scared feeling tended to emerge from those who had never seen a cleft before. Others experience more dramatic emotions, feeling paralyzed and depressed (Angelica) or desperate (Sofia). The cleft diagnosis took such an emotional toll on some parents that they wished death or harm upon themselves or their baby.

> “[I] wanted the baby to die. [I] said I hope God forgives me but I hope God takes away my baby” (Angelica).
>
> “When [I]saw the baby like that I didn’t want to have food. [I] didn’t want to eat. [I] didn’t want to sleep” (Susana).
>
> “[I] didn’t want to feed him. [I] wanted to die” (Paloma).

Although most parents expressed feelings that could be considered negative or pessimistic, the love for their child, excitement about having a baby, and desire to do whatever they needed to do was clear. In one instance when the mother refused to care for the baby, the father expressed his love for it and took on the primary caregiver role (Paloma). Another mother stated, “[I] was very excited about having a baby so [I] didn’t mind” (Guiliana), while the father who had seen the cleft during an ultrasound said he felt “normal” upon receiving the official diagnosis at birth (Enrique). Finally, two mothers had their baby taken away by hospital staff for multiple days following their births, so once being reunited any feelings of unease or sadness were gone and they were happy to be together and care for their child (Maria, Anita).

Initial Gaps

Once their situation was set, the questions and concerns each parent had created initial gaps that they needed to cross in order to make sense of the situation and provide the necessary care are support for their baby.

The initial questions parents asked can be categorized into three groups: those about the cleft, those regarding how to care for the baby, and questions about how to fix the cleft. Each, when paired with the emotions detailed above, demonstrates the individualized gap faced by each parent as they began their sense-making process. It is important to note, that most parents asked questions from two, if not all three, groups.

The first group of questions that parents asked was in regards to the cleft itself; what it is and why it occurred. They wanted to know what it was and why it happened. As one father stated, “[I] wanted to know why it happened, if there was a problem with something the mom was taking or with the doctor that helped the mom give birth” (Raul). A mother asked, “Why was the baby born like that? Was it a punishment from God? Was I a bad mother for having a baby like that? Why did it happen?” (Jacquline). As demonstrated in her questions, influences outside of medicine and genetics are believed to play a role in a child’s condition at birth. Another mother was told upon bringing her child to the hospital after a homebirth that the cleft was a result of giving birth at home and it was her fault (Sofia). Other parents attributed it to events during pregnancy. “[I] was asking [my] wife, why do you think this happened? Did you feel weird? Did you get scared?” (Enrique). In addition to wanting to understand the cleft and why it happened, one father wanted to know the cleft was only a physical impairment and “not a thing of the mind” (Jorge).

The next general group of questions asked upon diagnosis was about how to care for the baby. Wanting to provide for their child, most parents asked some version of "What can I do? How can I help her?" (Guiliana). The primary concern was how to feed the babies since most had limited ability to breastfeed (Gabriela, Enrique, Maria, Anita, Tomas, Raul). "[I] had lots of questions, but most important was how can [I] feed him?" (Jorge). One proactive father inquired about other tests that could be done to ensure that the cleft was the only problem and there was nothing else to be concerned about because the baby was born early (Enrique).

The final set of questions asked by parents upon receiving the cleft diagnosis regarded solutions or what could be done to fix the cleft. "How can I fix it?" (Guiliana). They wanted to know if there was a solution (Anita, Tomas, Miguel). As one mother explained, "every mother wants to have a baby that is completely normal" (Sofia), and surgery or a fix for the cleft would allow their child the opportunity to be considered normal.

Communication Channel Use

Upon receiving the cleft diagnosis and the creation of the situation and initial gap, parents immediately began their information seeking journey. When applied to the Sense-making model, this begins the process of building the bridge to cross the gap. For many it started with the doctor that delivered the baby, for others it took them to cities far away or to a communication channel many in the developed world might not turn to for health information (See Table 4.1). Each channel used was sought out for a different reason, provided a specific type of information, and left the parents with different emotions, and at times new unanswered questions. While the same channels were used by multiple parents, each perceived its helpfulness, quality of information, and ease of obtainability different.

Table 4.1

Use of Communication Channels for Health Information

	n	%
Medical Professionals	17	100
Friends and Family	14	82.4
Television	4	23.5
Internet	4	23.5
Radio	3	17.6
Other	2	11.8
Newspapers	0	0

The following sections discuss each channel used by the parents to gather information on clefts, from the most popular or commonly used to the least. While some parents expressed an order to their search, a friend told them to listen to the radio or the doctors were asked before family because they were closer, it is assumed that most communication channels were utilized in the same time frame in hopes of quickly obtaining information and thus care for their baby.

Medical Professionals

Of the parents interviewed for this study, all 17 talked with a medical professional, a doctor or nurse, to learn more about clefts after their baby was diagnosed. For many parents, the doctor that provided them basic information on clefts or told them it could be repaired was the doctor that delivered the baby, so he or she was not specifically sought out for informational purposes. Other parents went to a second doctor, whether it was a pediatrician or surgeon for more information. Often times doctors were used because of their medical knowledge. “[I] decided to go to doctors and nurses because [I] know they are smarter than most people” (Carmen). Others sought them out because they believed the quality of information they would provide was better (Carlos). For other parents it was a geographic decision, with multiple parents saying they went to a doctor simply because he was closer than anyone else (Jacquline, Susana).

Once connecting with these medical professionals, information obtained generally fell into the same three categories as the previously discussed initial questions that the parents had. For many parents the medical professionals were able to explain what a cleft was and at times why it happened. For one father a basic explanation of clefts was given instantly upon the doctors handing him the baby at birth (Raul). For others, a more detailed medical explanation was given. “Doctor told [me] that maybe could be because of vitamins during pregnancy or maybe [I] was taking any pills” (Carmen). For a few mothers however, finding out what caused the cleft was an upsetting experience with the nurses asking each what she did to cause the child to be like that. Was she on any pills or medication? (Gabriela), “What did you do to have your baby be born like this” (Jacquline). Another mother was told she was the cause of the cleft after giving birth at home (Sofia). No parent interviewed expressed doctors mentioning any of the common folklore causes of clefts, being scared or near lightening, but none received a full medical explanation on the etiology of clefts either.

For those parents concerned about how to care for their baby, medical professionals were able to offer information and tools to calm their concerns. In most cases this information focused on how to properly feed the baby. “The nurses taught [me] how to feed the baby, how to use the bottle" (Gabriela). While this mother felt she received full instructions and understood what she needed to do, other parents were left with only partial answers and no guidance. For one mother, the doctors where she gave birth only told her to try and hold the baby a certain way then left her alone in the room. It was not until she met with a pediatrician that the feeding process was explained in a way she felt comfortable with (Guiliana). One father was simply handed a syringe when he asked about feeding (Juan), while another was left to search for a second feeding process on his own when his baby refused food from the syringe (Miguel). In most cases it appears the medical professional had good intentions with the information provided, however, were not able to communicate it in a way that met the needs of the parent. This is apparent in one nurse's comment to a mother when teaching her to use a syringe for feeding that she had to do it "because if [I] wouldn't do that the baby couldn't feed another way and maybe she could lose some weight and maybe die" (Maria). The most comprehensive answers on feeding and care came from medical professional specialized in pediatric care. Whether it was a pediatrician or a specialist at the Children's Hospital, the feeding process was fully explain and demonstrated (Guiliana, Raul).

Finally, most medical professions were able to reassure the parents that there was a solution for their baby's cleft; there was a surgery and they had nothing to worry about (Carlos, Paloma, Jorge, Juan, Angelica). In some cases, seeking multiple medical opinion provided parents with a wealth of information, usually reaffirming what the previous doctor or nurse had said. However, this was not always true. One mother received conflicting information, "some said there was a solution and others said there wasn't" (Anita). Many doctors told parents that there were missions or campaigns that would come to Peru to provide these surgeries (Juan, Sofia, Raul, Miguel). However, these doctors often did not have a lot of information on the surgical process or the missions (Maria), making it clear that it was the parents' responsibility to find the missions and be alert to when they would be in town (Jacquline). This put responsibility for the child's care completely on the parents. A clear point of contention or perhaps misinformation among the doctors was the age at which they told the parent the child could receive surgery. The ages of one month (Maria), one year (Guiliana), three years (Enrique), and six years (Jacquline) were all given as thresholds for when their child could have surgery for their lip or palate.

While providing a wide range of information, satisfying most parent's initial questions, some felt information from medical professionals was missing or incomplete. In most cases where parents expressed that they felt information was missing, the reality was that they wanted more details to support or explain the information that was provided. "They didn't tell [us] exactly about the surgery and [I] felt [I] didn't have enough information" (Tomas). Other parents echoed this sentiment; wanting to know how long the surgery would last and how many surgeries their child would need (Raul). Parents who were taught how to feed their child with a feeding tube or syringe felt their education was missing critical instructions (Jorge), while others wanted more specifics on breastfeeding options for a baby with a cleft (Angelica). Finally, one father felt emotional support from the medical professionals was missing. "[I] wanted the doctor to tell [me] it would be ok" (Carlos).

Overall, information about clefts provided to parents by medical professionals was found to be helpful in answering their initial questions (Gabriela, Carlos, Guiliana, Enrique, Susana, Angelica) and providing a direct solution (Juan). These parents believed that they doctors told them “good things” (Carmen) that helped them provide and care for their child. Knowing there was a solution gave them hope (Jorge). One father stated he found the information helpful, however admitted that “at the time, [I] couldn’t pay attention to anything [I] thought wasn’t useful” (Raul).

Other parents were not as positive when discussing the helpfulness of information provided by medical professionals; however, the label appears primarily due to missing information. One mother felt she did not receive helpful information from the hospital because nothing they said was useful besides telling her there was a special bottle (Maria). Another felt his overall interaction with medical professionals was not helpful “because they didn’t know when and where were the missions” (Miguel). As mentioned earlier, one mother was told by some doctors that there was no solution and that the surgery was not offered in Peru, leaving her to find information from these doctors completely unhelpful and motivating her to search elsewhere for answers (Anita). The only instance that counters the notion of unhelpfulness being due to missing information is the mother who found the nurses who blamed her for the baby’s cleft to be unhelpful (Jacquline).

Many parents felt that it was easy to get and understand information from medical professionals, although it is not clear if this is because professionals were available at the time of the child’s birth or if they sought out additional experts. Most responses painted the picture of a direct communication process between the two parties. “It was not that difficult because when [I] asked the doctor answered” (Juan).

Other parents, however, encountered several barriers in connecting with medical professionals. “It was difficult. Some people didn’t let [me] talk with the doctor” (Carlos). Another father had trouble getting a doctor at the hospital to attend to him, but once he did, his questions were easily answered (Tomas). Others were able to easily talk to medical professionals, but felt their concerns were being ignored. One mother felt the professionals were bored with a poor disposition and were “answering just to answer” and not to help her (Jacquline). Finally, one mother faced a language barrier that made the health information difficult to get and understand. Coming from a rural area in Peru she spoke an indigenous language called Quechua and not Spanish, creating difficulty in understanding the doctors and them understanding her (Susana).

After their conversation with medical professionals, some parents felt they had received satisfactory answers to all their questions (Gabriela, Carlos, Miguel). Others developed new questions. Some questions were in direct response to new information they received. Those that learned that there was a surgery to correct the cleft wanted to know more about it. “[I] wanted to know what [I] had to do before surgery, during surgery, after surgery. How was the feeding going to be?” (Guiliana). Others had questions and concerns about the specifics of the surgery (Carmen) and how to care for their child and his wound after (Susana). These same parents are the ones that felt more detailed information about the surgery was missing. Other parents, once talking with medical professionals, had question about information they had received from prior sources. One father questioned the age requirement he was previously given for his child to receive surgery (Enrique), making him question if he could have had it done sooner. Another parent questioned if there was a faster solution, motivating him to turn to other medical professionals and communication channels for information (Jorge). One father said he questioned his own actions, asking “why didn’t we do this? why didn’t we have more care with the baby?” (Raul). While many parents shared that new questions did arise, it is unclear if they voiced these questions to the medical professionals. One father admitted, “[I] wanted to ask more. But at the same time [I] was very quiet because [I] knew [I] was receiving good information” (Enrique).

After initial information gathering with medical professionals, most parents expressed experiencing positive emotions. “[I] felt relief in my heart with that information” (Susana). Most explained their feelings of quiet or relief were due to learning there was a solution (Tomas, Raul) or as one father put it, he felt “glad and happy because [I] found there was a solution for [my] girl” (Miguel). One mother, although happy to have the new knowledge, developed feelings of desperation to have the surgery done (Carmen). A second group of parents left the interaction with negative feelings about their current situation. The mothers that were blamed for their children’s clefts felt guilty and upset (Jacquline, Sofia). One mother was scared after receiving the information (Paloma), while one father was doubtful of all the information he received (Carlos). Those wanting answers for previous or new questions often left with a sense of desperation for more information (Maria).

Friends and Family

After medical professionals, friends and family were the second most utilized communication channel used by parent to gather information about clefts, with 14 of the interviewed parents reaching out to those close to them. Most expressed choosing this channel because of the established relationship and bond between the groups. “[I] had a lot of trust in [our] families so [I] decided to go to them and go where they said" (Carmen). "[I] thought I trusted in [my] family and was hoping that [I] could continue that" (Jorge). Others decided to ask relatives because of geographic location. One mother lived with her family, so they were easily accessed (Jacquline). Others that lived in more remote areas of the country appealed to the knowledge of those living in bigger cities. "[I] asked some family [I] had in Arequipa" because they were there (Carlos). Several parents revealed that they did not reach out to friends or family for information (Guiliana, Enrique), with the general reason being that they had no experience with the situation and would not be able to answer any questions.

For some parents, turning to friends and family ended up being a misguided journey with no information being obtained. "They just didn't know. [I] asked some of them but they didn't answer anything. They didn't know. Just didn't know" (Susana). For many the lack of knowledge was attributed to never having encountered another person or child with a cleft (Juan).

For many, friends and families were not able to provide a medical explanation or instructions for care, but relayed information about missions coming to Peru where the child could be seen (Maria, Anita, Miguel). One mother was told that it was a genetic condition (Carmen), while others were blamed or asked by their family what went wrong (Jacquline, Miguel).

In other instances, information about clefts was not obtained, but moral support was (Jacquline, Angelica). "They gave [me] a lot of support after [I] left the hospital because they all told [me] that they were going to help (Jacquline). One mother, scared to show her child to others, was visited by a friend who told her there was nothing to be ashamed of and that she should just take good care of the baby until its surgery (Sofia).

For some parents their friends and family served as a middleman, delivering information from a different communication channel. One father's nephew brought him information on feeding that he had found on the internet (Raul). Other relatives brought brochures they found at the hospital (Jorge), while some told the parents about the missions they had heard about on the radio (Anita, Miguel).

Although the scope of information received from friends and family was limited, none of the parents interviewed expressed feeling that information was missing. One parent, however, classified going to his family as unhelpful because a full explanation of the process was not given to him (Carlos).

Overall, most parents found the information received to be very helpful (Maria, Tomas, Miguel, Angelica) for different reasons. One mother found it helpful because it was when she learned for the first time there was a surgery for her child (Carmen), while another likes the motivation it gave her to take good care of her baby (Sofia).

Reaching out to family and friend was an easy task for most parents (Sofia, Thomas, Angelica). For some it was because a similar language (not Spanish) was spoken, making the information transfer easier (Miguel). For others it was simple because they were with friends (Sofia, Miguel). The one father that found obtaining information from family difficult attributed it to a large geographic distance between his rural home and his family in the city that made him uncomfortable asking (Carlos).

After talking with friends and family, a few parents had new questions about the information they received. "[I] wanted to have more information on what the family had told" (Carlos). These parents wanted more information regarding surgery, when it would be (Miguel) and at what age the child was eligible (Carlos). One mother wanted to ensure that her child's palate could be corrected in addition to its lip (Maria). The new questions served as motivation for them to turn to other communication channels to get information (Miguel).

As most would assume, after talking with friends and family, the parents of the children with clefts felt happy, quiet and relieved (Jacquline, Maria, Anita, Tomas, Miguel, Angelica). Many attributed these feeling specifically to knowing the baby would have surgery (Maria, Anita, Miguel). One father left these interactions feeling doubtful about the information he had received because no one told him the baby would be alright (Carlos). One mother, although happy there was a surgery was still very sad because her new questions and concerns took away the joy of surgery being a solution for her child's cleft and the end of their current situation. "[I] was concerned too how the baby was going to talk, how was going to be her speech because [I] had seen some other with the cleft, some other babies, and they had not good speech" (Maria).

Television

Four of the parents interviewed used the television to gather information about clefts. Three of these parents learned about the missions that would be coming to Peru to provide surgeries (Carmen, Enrique, Maria). One father, however, felt information was missing on what age the child could have the surgery (Enrique). Another father watched programming about the surgery. "[I] saw more or less how the process was," but would have liked more information about the care he needed to take with the baby (Raul). Even with wanting more information, television was found to be easy to use and helpful, with one mother wanting to share it with everyone else in her town experiencing the same thing (Maria).

Internet

Even with the limited knowledge of and access to the internet in the studied population, four of the parents interviewed utilized it to search for information on clefts upon receiving the diagnosis. Each parent search for and found very different types of information. One mother, very concerned about stereotypes of kids with clefts, “went to the internet, not because [I] think it is exact information, but because [I] could know something more about the babies” (Jacquline). She also searched for Operation Smile and information on why her baby was born like that. “[I] found that it was because of malnourishing, weather conditions, vitamins” (Jacquline). A second mother used the internet to find a pediatrician that could refer her to a surgeon, as well as information on positions for the baby to eat and sleep in (Guiliana). A father shared, “[I] went to the internet because [I] thought [I] could find advice and instructions for how to keep the baby. Especially how to care for the baby, especially in feeding. [I] found there were special bottles and nipples so [I] can feed the baby in the right way” (Jorge). He also learned that there were many causes of clefts and the mother did not do anything wrong (Jorge).

These parents found the information they received to be helpful (Jacquline, Jorge); however, the fourth parent that accessed the internet did not find any information she found to be helpful (Maria). The information left one mother concerned about the real cause of her baby’s cleft (Jacquline). One father shared his difficulty getting information from the internet, not because of the technology, but because he had to travel a long distance from his town where there is no internet to a bigger city to find it (Jorge).

Radio

Of the parents interviewed, three shared that they had learned something about clefts or caring for their child with one from the radio. For all three, the information heard detailed surgical missions coming to Peru. "[I] heard on the radio that there were going to be these missions, so [I] knew there was a solution with the surgery and [I] was happy with that information" (Sofia). Two parents did not question the information and instantly decided to come to the mission (Carmen, Sofia); however, one of them wished the dates had been repeated more (Sofia). For one mother, information she heard on the radio motivated her to ask her friends and family for more information (Angelica). Radio communications were labeled as very helpful (Carmen, Angelica) and feelings of happiness and relief were shared among these parents after learning of the missions (Sofia, Angelica).

Other Channels

Two of the parents interviewed mentioned receiving information from other channels, although when probed did not go into great detail. One mother read about the upcoming mission on fliers and posters around the streets in her town (Anita). Another father learned about the missions from the mining company in his town (Tomas), although he could not clarify if it was from a personal interaction or an advertisement.

Closing Remarks

At the conclusion of each interview, parents were asked if there was anything else they would like to share about having a child with a cleft or their experiences that they believe would be beneficial for the researcher to know. A few had nothing else to say (Susana, Anita, Miguel), while others reiterated their happiness and thankfulness for a solution and organizations like Operation Smile (Jorge, Sofia). Remarks by some parents showed that while they ultimately bridged some of the gaps they faced and had reached the point of getting surgery for their child, there were other gaps they were still waiting to cross. “[I am] still very concerned about why it does happen” (Enrique). These thoughts were echoed by other parents whose initial questions were not answered (Tomas). One mother shared that she believes that asking why it happened is not as important as other things (Jacquline), demonstrating her decision to ignore that gap all together.

Other parents made remarks that implied how their experiences could have been improved. One mother wished advertisements for the mission had been more prevalent outside of the mission city, stating that having them where she lives, in a city far away, would have been nice (Maria). Two fathers expressed that seeing other children like theirs was helpful (Enrique, Raul). Several parents conveyed that the ability to share their information or experiences with other parents would be good, perhaps a practice they would have found beneficial during their information gathering. “[I] feel like [I] can share with other parents and other people about the procedure and what [I] know” (Raul). Parents wanted others to know that surgery was available (Carlos), they do not have to feel desperate or scared (Guiliana), and that they can be comforted because their babies will be pretty (Gabriela).

Finally, a few parents made comments that noted the creation of new situations and thus new gaps and sense-making processes for themselves and others. One father, now that his baby had the surgery, wanted to know more about the surgery, what comes next, and will there need to be more surgeries (Juan). One mother, using the surgery as a new starting point, questioned what life would now be like for her child. “[I] want to know about the baby, if she can go Monday to school” (Angelica). While these parents created new situations for themselves with a baby now considered fixed, one mother acknowledged that a sense-making process would one day have to be undertaken by her child. He would one day ask her, “What did you do mom to make me like that?” (Jacquline); a question that begins a new journey of information gathering and gap bridging.

CHAPTER 5

SURVEY RESULTS

Complimentary to the qualitative interviews, a quantitative survey was administered to better understand health information seeking behaviors of parents of children with cleft lips, as well as the overall credibility level assigned to health information from a variety of health communication channels. The aim of the survey was to not only better understand the prior behaviors of the parents of children with clefts, but to evaluate how health communication channels can be more effectively used to reach remote populations in developing countries, potentially with low literacy levels and low socioeconomic status.

Respondents

At the Operation Smile mission, all parents of children with cleft lips and/or palates were recruited to participate in the survey portion of the study (*N* = 45). Of that, 68.9% (*n*=31) were mothers and 31.1% (*n* = 14) were fathers. The mean age for parents was 32.84 (*SD*= 8.16) and their children with a cleft had a mean age of 3.727 (*SD* = 3.98), making the sense-making process studied fairly recent for most parents. A majority of parents were fairly educated with 28.9% (*n* = 13) finishing high school and 24.4% (*n* = 11) completing university studies; however, 24.4% (*n* = 11) reported only completing primary school. A strong majority, 84.4% (*n* = 38) reported no history of clefts in their family, while 15.6% (*n* = 7) had at least one family member who had a cleft. Finally, an overwhelming majority, 95.6% (*n* = 43) said they found out their baby had a cleft after it was born, with only 4.4% (*n* = 2) finding out before the baby was born.

Communication Channel Usage for Cleft Information

To answer RQ2, all respondents were asked to select from a provided list which communication channels they had used to collect information about clefts once learning their child had one (See Table 5.1). They were asked to mark all channels that applied. Television, radio, newspaper, the internet, family and friends, and medical professionals were all options provided, as well as "I Don't Know" and "Other" categories.

Almost all respondents stated that they used medical professionals to get information about clefts (*n* = 42), followed by just over half noting the use of friends and family to gather information (*n* = 25). These results support H1 that predicted interpersonal communication channels would be predominantly used. Use of television and radio were approximately equal, with a large gap between their usage rates and those of the internet and newspapers. The one respondent that marked "Other," noted that they turned to Operation Smile to collect information.

Table 5.1

Use of Communication Channels for Cleft Information

	n	%
Medical Professionals	42	93.3
Friends and Family	25	55.6
Television	21	46.7
Radio	22	48.9
Internet	9	20.0
Newspapers	8	17.8
Other	1	2.2
Didn't Know	0	0

Relationships Between Channel Selections

Several weak yet statistically significant correlations between the selections of communication channels for obtaining health information were found (See Table 5.2). First, a positive correlation was found between using television to gather information about clefts and using the radio to find information on the same topic (r = .333, $p \leq .05$). Another positive correlation was found between those who read newspapers for cleft information and those who selected "Other," denoting use of a channel outside of those provided as options (r = .324, $p \leq .05$). A negative correlation was found between those who use their friends and family to find information on clefts and those who use the internet for it (r = -.335, $p \leq .05$). Finally, a moderate negative correlation was reported between those who gathered cleft information from medical professionals and those who selected the "Other" option and noted Operation Smile as the other source (r = -.564, $p \leq .01$).

Table 5.2

Correlations in Communication Channel Use

	Medical Professionals	Friends & Family	Television	Radio	Internet	Newspapers
Medical Professionals	–					
Friends & Family	.120	–				
Television	.071	.030	–			
Radio	.083	.159	.333*	–		
Internet	.134	-.335*	.200	.067	–	
Newspapers	-.109	.182	.264	.243	-.087	–
Other	-.564**	-.169	-.141	-.147	-.075	.324*

Notes: $^*p \leq .05$; $^{**}\ p \leq .01$

Perceptions of Channel Informativeness

To address RQ2a and better understand the usability of various health communication channels, respondents were asked to select which of the communication channels they used to learn about clefts was most informative, least informative, easiest to understand, and hardest to understand. Slightly more than half of the respondent who turned to medical professionals for information found them to be most informative (*n* = 23), followed by a large drop to family and friends (*n* = 7) and television (*n* = 6,) (See Table 5.3). These findings support H2. Results for the communication channel found to be least informative were less drastic. While friend and family were found to be least informative (*n* = 10), collecting just under a quarter of the votes, the channel was within seven percentage points of television and the radio. Twenty percent of respondents (*n* = 9) were unable to decide which was least informative, directly contrasting the zero percent that could not select a most informative.

Table 5.3

Informativeness of Communication Channels for Health Information

	Most Informative		Least Informative	
	n	%	*n*	%
Medical Professionals	23	51.1	4	8.9
Friends and Family	7	15.6	10	22.2
Television	6	13.3	7	15.6
Internet	4	8.9	3	6.7
Radio	3	6.7	7	15.6
Other	1	2.2	1	2.2
Didn’t Know	0	0	9	20.0

A series of chi square tests were used to determine if there is a relationship between communication channels used to find information on clefts and the channel selected as most informative. Significant results were found for several channels. Selection of the most informative communication channel by those who used newspapers was found to be statistically significant, $\chi^2 = 12.518$, $p = .028$. Of those users, television, radio, and medical professions were found to be the most informative communication channel for obtaining information about clefts, with each being selected by 25% ($n = 2$) of respondents. None selected newspapers as the most informative. Respondents who noted use of the internet to find information on clefts provided statistically significant results, $\chi^2 = 18.748$, $p = .002$, with 44% ($n = 4$) of users finding the internet to be the most informative channel, followed by medical professionals at 33.3% ($n = 3$). Statistically significant findings were found for respondents who noted using friends and family to gather information on clefts, $\chi^2 = 12.786$, $p = .025$. While 29.2% ($n = 7$) of these users found friends and family to be the most informative, the majority, 45.8% ($n = 11$), found information from medical professionals to be the most informative. Finally, those who used medical professionals to learn more about clefts, demonstrated statistically significant results in the channel they selected as most informative, $\chi^2 = 17.392$, $p = .004$. In these cases, over half, 56.1% ($n = 23$), found medical professionals to provide the most informative cleft information. They were followed by friends and family at 14.6% ($n = 6$).

Perceptions of Channel Understandability

In the same way they were asked to pick the most and least informative channel for gathering information about clefts, respondents were asked to pick which of the channels they used was easiest to understand and hardest to understand (See Table 5.4). Again supporting H2, medical professionals were rated as providing information that was the easiest to understand (*n* = 20, 44.4%), however, almost one third of respondents found them to be the most difficult to understand (*n* = 12, 26.7%). Television followed by friends and family ranked as the second and third easiest to understand, while television, radio and the internet were found to have similar levels of difficulty to be understood. Interestingly, friends and family, with ranked third for ease of understandability (*n* = 6, 13.3%), had the lowest ranking of provided channels for difficulty to understand (*n* = 4, 8.9%).

Table 5.4

Understandability of Communication Channels for Health Information

	Easiest to Understand		Hardest to Understand	
	n	%	*n*	%
Medical Professionals	20	44.4	12	26.7
Television	10	22.2	7	15.6
Friends and Family	6	13.3	4	8.9
Radio	2	4.4	6	13.3
Internet	2	4.4	5	11.1
Didn’t Know	2	4.4	8	17.8
Other	1	2.2	1	2.2

Statistically significant results were also found in the relationship between communication channel use and the selection of a singular channel as easiest to understand when trying to learn about clefts. Respondents that used television to learn about clefts provided significant results, $\chi^2 = 18.333$, $p = .005$, with 52.6% (*n* = 10) finding it the easiest to understand. This was followed by medical professionals at 26.3%

(*n* = 5). Radio users also provided significant findings in the channel they found to be the easiest to use, $\chi^2 = 13.784$, *p* = .032. A majority of these users, 38.1% (*n* = 8), found television to be the easiest to understand, followed by medical professionals that were selected by 28.6% (*n* = 6). Finally, findings were statistically significant among the group that used medical professionals to learn more about their child's cleft, $\chi^2 = 16.292$, *p* = .012. Among medical professional users, 50% (*n* = 20) found them to be the easiest to understand, with television coming in a distant second with 22.5% (*n* = 9) of respondents finding it the easiest to understand.

Credibility of Health Information from Communication Channels

Apart from understanding what communication channels survey respondents actually used to learn about clefts, they were asked their overall opinion on health information coming from various communication channels to answer RQ3 (See Table 5.5). An adapted version of Hallahan's (1999) believability scale was used, with an index being created for each communication channel. Alphas for each index ranged from .92 for the friends and family index to .95 for the medical professional index; all well above the acceptable .70 threshold.

Overall, health information from medical professionals was rated most credible (*M* = 20.11, *SD* = 3.82). Information from television was rated the second most credible, followed by health information from radio. This only partially supports H3, while support of H4 is debatable. The internet had the lowest scoring credibility index (*M* = 16.13, *SD* = 4.48), however, one-third of respondents (*n* = 15) did not know what the internet was and left the question blank. For all channels, except friends and family, informativeness was the highest rated factor.

Table 5.5

*Credibility Index Means and Standard Deviation**

	M	*SD*
Television (alpha=.94)	18.02	4.22
Accurate	3.36	1.07
Believable	3.71	0.87
Trustworthy	3.69	0.87
Informative	3.71	0.90
Convincing	3.56	0.94
Radio (alpha=.93)	17.67	3.98
Accurate	3.33	0.93
Believable	3.35	0.92
Trustworthy	3.51	0.95
Informative	3.76	0.83
Convincing	3.53	0.87
Internet (alpha=.94)	16.13	4.48
Accurate	3.10	1.06
Believable	3.30	0.99
Trustworthy	3.13	0.97
Informative	3.50	0.94
Convincing	3.10	1.00
Newspapers (alpha=.93)	16.60	4.04
Accurate	3.20	0.99
Believable	3.22	0.95
Trustworthy	3.18	0.96
Informative	3.56	0.79
Convincing	3.44	0.84
Friends and Family (alpha=.92)	16.59	4.31
Accurate	3.36	0.96
Believable	3.42	0.89
Trustworthy	3.32	1.01
Informative	3.38	1.03
Convincing	3.13	1.04
Medical Professionals (alpha=.95)	20.11	3.82
Accurate	3.87	0.89
Believable	3.96	0.85
Trustworthy	4.00	0.91
Informative	4.14	0.80
Convincing	4.04	0.85

Notes: *Adapted from Hallhan, 1999 to a 5-point Likert scale

A series of independent sample t-tests were conducted to understand the credibility levels assigned to various communication channels as sources of health information based on whether a respondent used that media for that purpose. Statistically significant results were found. First, those who used the radio to gather information about clefts found health information from friends and family to be less credible, $t(42) = -2.523$, $p = .016$. Those that use the radio found friends and family to be a less credible source of health information ($M = 15.05$, $SD = 4.59$) than those who do not use the radio for that purpose ($M = 18.14$, $SD = 3.45$).

Those that use the radio also found health information from medical professionals to be less credible than those who did not use the radio to find health information, $t(42) = -2.452$, $p = .018$. On average, those who use the radio ($M = 18.71$, $SD = 3.52$) found health information from medical professionals less credible than those who did not use the radio ($M = 21.39$, $SD = 3.70$).

Another independent t-test provided statistically significant results for the credibility assigned to health information from the internet by those who do and do not use it to search for information on clefts, $t(28) = -2.308$, $p = 0.29$. Those who used the internet to gather health information about clefts, found general health information on the internet less credible ($M = 13.44$, $SD = 2.28$) compared to those who do not use the internet ($M = 17.29$, $SD = 4.48$).

T-test found two significant results in assigned credibility levels by those who used their friends and family to gather health information. First, a statistically significant difference was found in the credibility level assigned to health information in newspapers, $t(43) = 3.09$, $p = .004$. Respondents that used friends and family to get cleft information attributed a higher level of credibility to health information from newspapers (*M* = 18.12, *SD* = 3.41) than those who did not (*M* = 14.70, *SD* = 4.03). Second, those that used friends and family to gather information about clefts attributed a lower level of credibility to health information in general from medical professionals (*M* = 19.03, *SD* = 4.30) than those who did not use them (*M* = 21.35, *SD* = 2.78), *t*(42) = -2.03, *p* = .049.

An independent sample t-test was performed on each credibility index, with no statistically significant difference found in assigned credibility based on gender.

Comparison of Perceived Informativeness and Credibility

A series of ANOVAs with Bonferroni post hoc tests were performed, with only credibility assigned to health information from medical professionals showing a main effect, *F*(2, 32) = 7.343, *p* = .002. Statically significant results showed that those who believed medical professionals were the most informative source of information about clefts, found information from them more credible than those who believed their friends and family were the most informative source of information about clefts, with a mean difference of 5.51, *p* = .004.

CHAPTER 6

DISCUSSION

As demonstrated in the qualitative interview and quantitative survey results, the sense-making journey undertaken by each parent following the cleft diagnosis of their child is extremely individualized; however across the population studied, trends in emotions, behaviors, and attitudes can be seen. While Sense-making results are often subjective (Savolainen, 2006) and difficult to generalize to populations outside of the specific one observed, results from this study demonstrate the need for the improvement of health communication practices regarding clefts within this rural Peruvian region and provide several opportunities for such action in each communication channel examined.

Proving of particular influence on information seeking behaviors used during the sense-making process are culture and the perceptions of channel credibility of different communication channels as health information sources. Once understanding parental informational and emotional needs and these motivational forces behind communication channel selection for purposes of cleft research during the sense-making process, health communication efforts can be better designed to meet the needs of parents of children with clefts in this area of Peru. While communicators cannot be absolutely sure how an individual will evaluate or process a message about clefts, they can ensure that accurate information is provided through appropriate communication channels. Results also provide implications for the inclusion of communication theory in the design and dissemination of communication efforts to reach the population in Juliaca more effectively, as well as recommendations for using Sense Making as a framework for research and program planning in other developing country settings.

The Situation and Gap Approach

While the sense-making process is often found to be very individualized, the situation established at the point of diagnosis seems to be rather universal, providing insights as to how health communicators should focus their messages. Most parents interviewed and surveyed received the cleft diagnosis upon the birth of their child due to the lack of medical care and/or availability of detection technology, as was common before advanced technology began being used for prenatal screening in developed countries (Strauss, Sharp, Lorch, & Kachalia, 1994). The initial questions asked by each parent upon diagnosis were easily categorized into three groups. Most parents wanted to know why it happened, how it can be fixed, and how to care for their child in the meantime. In terms of sense-making verbs, they wanted information to define, understand, and fix. These categories are supported by previous research that found parents of children with clefts overwhelmingly wanted to know how to take care of their baby and that it was not their fault it happened (Young, O'Riordan, Goldsteing & Robin, 2001).

The sadness, fear, and depression experienced by the studied parents also appear to be common in other parent populations. Upon receiving a cleft diagnosis feelings of shock (Nusbaum, 2008), grief, and disappointment are commonly experienced (Nelson et al., 2012). Huber found that these emotions may be due to the loss of the imagined perfect child the parents had been anticipating during pregnancy (as cited in Beaumont, 2006). Extreme emotions expressed by parents interviewed, such as wishing death for themselves or their baby (Angelica & Paloma), maybe in part attributed to cultural beliefs on the cause of clefts; particularly the large number of parents in Peru that have a strong internal attribution for the cause of their child’s cleft (Mednick et al., 2012). Prior experience, particularly a family history of clefts, can influence perceptions of the cleft (Rey-Bellet & Hohlfeld, 2004) and thus corresponding emotions.

Although the situation is slightly altered for each parent depending on their specific experiences or questions about clefts, their starting point is a place characterized by a lack of information and knowledge. The resulting gaps created are approached with an overwhelming flood of emotions and a desire to understand and make sense of the cleft diagnosis in order to ultimately provide for their child. It is this approach of the gap, which appears to be strongly driven by cultural influences, that motivate the direction of and reactions to the sense-making process for each parent. Health communication practitioners should acknowledge the emotional and informational components of the sense-making process when evaluating the initial information needs of their target population and how to meet them quickly and effectively.

Medical Professionals

The use of medical professionals was the most popular method of information seeking for both the interviewed and surveyed parents, understandable due to the increased medical knowledge participants attributed to them over other channels or sources. Their use, perceived by some as helpful and by others as not, served to help and impede the parent’s sense-making process depending on how the interaction played out.

Medical professionals were able to successfully explain to most parents what a cleft was; however, very few gave a medical explanation of why it happened or discussed any of the folklore causes shared in the interviews. Again this gave parents the opportunity to define the condition, but not a reason why it happened, thus not helping to eliminate any feelings of shame or guilt felt by the parents. This omission may demonstrate a lack of medical knowledge on the cause of clefts by non-pediatric or maxio-facial doctors, but it may also be due as Hutchinson explained, to individuals, including the doctors, believing folklore explanations about the causation of clefts more than medical ones (as cited in Mednick, 2012).

Additionally, medical professionals were often able to provide basic answers to most parents' initial questions, helping them understand clefts better. For some, they provided instruction on what they needed to do to feed or care for the child, while others were left struggling because the instructions were not enough. The answers given by medical professionals in addition to parents' corresponding new questions, and perceptions of missing information, highlight a potential lack in quality information being distributed by this expert communication channel. This lack of information or inclusion of inaccurate instructions or ideas impeded or slowed the sense-making process because a true evaluation of the information could not take place in order to make a decision on how to act in their given situation. This behavior provides the opportunity for health communicators to evaluate what audiences their messages will have a greater influence on.

Power played an important role in interactions with medical professionals. While the creation of new questions can be interpreted as the completion of crossing the initial gaps created at the point of diagnosis and the arrival at a new one, it may also be perceived as a challenge to medical authority or an expression of wanting to verify the information that was received through more detail. The act of going to a second medical professional or another source of information also demonstrates a power struggle that challenges the traditional doctor-patient relationship (Beisecker, 1990). While these behaviors transfer power over the interaction to the parents, giving them stronger control of their sense-making process, it presents a chance for conflicting information to be obtained from another channel. This possibility increases the need for medical professionals to be able to provide complete and accurate information upon diagnosis. While parents that decided to stay silent and not ask any more question even if they had one preserved the doctor's power in the relationship, it did not help their sense-making process move forward. Behaviors by these parents demonstrate that in interaction with medical professionals, challenges to and struggles with power are useful in the sense-making process.

Aside from factual medical information, interviewed parents expressed a need for moral or emotion support from medical professionals (Carlos); an assurance from the source they perceived as having ultimate knowledge that everything would be alright. The lack of moral support is not uncommon from medical professionals after a cleft diagnosis (Strauss, 1994), a gap that the field should try harder to fill. Although this cannot be done by outside health communication practitioners focusing on clefts, it does provide an opportunity for national and local health centers to improve their services through training; a point at which health communicators could design and provide cleft education materials or trainings for medical professionals.

A crucial outcome of increased interpersonal training and cleft education for medical practitioners would be the elimination of the assignment of blame by the nurses experienced by Jacquline and Sofia and the frustration associated with being ignored like Tomas or not understood due to a language barrier like Susana. With better patient interaction skills and a basic knowledge about clefts and what a mother or father should immediately be told upon diagnosis, medical professionals can help calm the fear and guilt felt by parents and answer many of their initial questions, assisting them in crossing their initial gaps faster and allowing their sense-making journey to focus on the future.

Although the qualitative interviews provided insight into what can be seen as the positive and negative aspects of using medical professional as information sources in the sense-making process, survey results strongly support their use. As previously discussed, the utilization of medical professionals may be due to perceptions of elevated knowledge regarding health or the parents' preference to use an interpersonal channel to obtain health information. Parents found medical professionals by far to be the most informative and easiest to understand channel used on their personal search for information on clefts. Additionally, when looked at on a broader scale, general health information from medical practitioners was perceived to be more credible than information from any other channel. These results note a success on the part of medical practitioners in Peru, because although it is common for information from medical professionals to be considered the most credible, it is often deemed hard to understand (Wathen & Burkell, 2002).

Results demonstrate that education of medical professionals about clefts may have a greater impact on the sense-making process of the studied population than direct communication with parents and should be evaluated as a possible strategy by health communication practitioners. Because every parent discussed clefts with a medical professional at some point, if accurate information could be given at this time the sense-making process would be aided and information from other channels could serve as talking points for discussion with medical experts or confirmation of what the medical professionals said.

Friends and Family

Friends and family, or those that can be categorized as a lay interpersonal channel from which to gather information on clefts, was the second most popular channel used by study participants, supporting research claims by Greenhalgh, Helman, and Chowdhury (1998) that family input is highly valued when it comes to health; although usage rates were far less than that of medical professionals. Unique to this communication channel, no parent specifically mentioned believing that information was missing from their friends and family. While some had new questions as a result of the interaction that motivated them to continue their information seeking and sense-making process, most were grateful and happy to receive the information they did. So it is assumed that use of the channel was beneficial to the sense-making process for parents that received any type of information.

While it was usually tidbits of information about clefts or a surgical mission rather than in-depth information that was obtainable from this channel, two important trends were noticed in the results. First is the role friends and family played as middle men for the transfer of information. In many cases, friends and family did not draw upon their own knowledge or personal experiences with clefts when interacting with the parents, but rather they shared information they had heard or seen through other communication channels. This role was valued by parents that did not have access to other channels such as the internet and explained the behaviors of turning to relatives in larger cities for information because they had access to different resources. While some parents reached out to extended family in the bigger cities, others preferred to stay closer to home, asking the immediate family that they lived with and were closest to. These behaviors introduced the influence of geography into the sense-making process, which is assumed to be particularly impactful in information seeking in developing country settings that have disparities in access to health information.

The second trend observed in those receiving information from friends and family is the ability for lay interpersonal connections to provide moral and emotional support for the parents following their child’s diagnosis rather than information. While this kind of connection or relationship was absent in interactions with medical professionals, it was popular in lay interpersonal situations. For two parents, support and encouragement were the main benefits received from friends and family, with both having a dramatic impact on the parent’s emotional status. Family support has been proven to increase self-efficacy (Torres & Solberg, 2001), which in the case of taking care of a special needs child is important. For many parents, this established bond and relationship of trust was the motivation behind information seeking behaviors directed toward this channel. In cases where the use of friends and family for information was excluded by parents in their sense-making process, the elimination was attributed to the assumed lack of knowledge about clefts within the group. This rejection left parents without a reason to connect and establish a much needed support system, leaving them alone on their sense-making journey. Thereby having neither emotional nor informational needs met.

The successful use of friends and family as conduits for cleft information, the ability to reduce the influence of geography, and to create a moral support system are strong arguments for the utilization of lay interpersonal communication channels following a cleft diagnosis. Through increasing knowledge of clefts in the general public the likelihood that accurate information is shared within an interpersonal network is increased, as is the ability to build informed support systems; both of which benefit the sense-making process of parents.

Results of the survey, however, challenge this notion. Almost a quarter of respondents that used the lay interpersonal channel to gather information about clefts noted that friends and family were the least informative channel and the overall credibility level of health information from it was low, ranking only above information from the internet. With these rankings and designations, it can be assumed that even accurate information shared by friends and family may not be paid the attention it is deserved. It is therefore logical for health communicators to recommend or suggest the use of friends and family as a resource for emotional support and promote medical professionals as a resource for information during the sense-making process, all while working to educate the general public to achieve the benefits mentioned above.

Television

Although television was used by just under half of the parents surveyed in an attempt to learn more about clefts, only four of those interviewed shared that they actually found information about clefts through the channel. While there is a large discrepancy in the success of finding helpful information when compared to the attempts, the information found demonstrates the versatility of messages on television for broadcasting information about clefts. Parents learned about the upcoming surgical missions, most likely from commercial advertisements sponsored by an aid organization, as well as the actual surgical process, assumedly from other programming. In terms of verbing, it gave parents a time and place to fix and the ability to understand that fix.

Television, even as a popular channel for information seeking, provided mixed results on the levels of informativeness and understandability of provided information about clefts. While it was ranked the second most informative communication channel to obtain information about clefts by users overall, almost a quarter of users found it to be the least informative. The channel fared better when rated for understandability. Although maintaining a second place ranking in both categories, more users found television to be the easiest to understand channel than the hardest. These results allude to a potential benefit in using television as a channel to communicate about clefts. Although survey respondents were not asked about what type of programming they used to gather information on television, if health communicators used popular programming to educate about clefts, audiences would be much more receptive to their messages because information would be presented in a way they are comfortable consuming. Use of the channel in this manner could potentially reach the 60.9% of the Peruvian population that have a color television in their home (Zeta de Pozo, 2009), including both active and passive information seekers. This means parents of children with clefts, members of their interpersonal networks, and the general public would all benefit. Messages would also be taken seriously and evaluated accordingly due to the high level of credibility parents assigned to information from television, falling behind only information from medical professionals. Although source credibility was not addressed in this study, using medical professionals as informational sources on television would further increase message effectiveness.

Information on medical mission will most likely always be restricted to short advertising spots from aid organizations on television that provide dates and locations; and while efforts should be made to include other desired information like age requirements for surgery, other types of television programming have the potential to provide more information and bring clefts into the main stream media due to popular culture characteristics of the studied population. In Latin America, daily soap operas or telenovelas are one of the most popular forms of entertainment, drawing in hundreds of millions of viewers and making them a good vehicle for educational messages (Jacobson, 2012). In Peru, 52.8% of the population watches these soap operas (Zeta de Pozo, 2009). As demonstrated in the incorporation of a character with Asperger’s Syndrome in the national Venezuelan telenovela, *La Mujer Perfect* (Acosta-Alzuru, 2013), television characters have the ability to share personal health narratives through storytelling. While the timing of such a plot line may not correspond with a parent’s sense making of a diagnosis, through this method passive audiences would become familiar with the idea of clefts. Television would allow audiences to visually see a cleft and potentially watch a storyline of a baby’s cleft repair, which would drastically influence their own sense-making process should it ever occur. The story, if accepted by the viewer as applicable, could then be used as a point of reference and a basis for future decision making (Fisher, 1985).

By watching a mother interact with a medical professional on television, parents would unconsciously be learning about clefts before they know the information will be relevant to them; knowledge that can be drawn upon later in their own communication with doctors following the birth of their child. Awareness about clefts would also be raised in audiences that will never have to experience sense making of a cleft for their own child, but may be included in the lay interpersonal network of another parent. By drawing on what they saw on the telenovelas they will be able to provide a stronger support network and perhaps guidance for parents that are on a sense-making journey. In Mexico, *Acompañame*, successfully used storytelling to shift public perceptions and slow the quickly rising population rate in the country (Laveaga, 2007). Such a plotline about clefts would help to shift public perceptions of the condition and eliminate the stigmas commonly associated with it, again helping calm the concerns and worry felt by new parents regarding acceptance and treatment of their child in society.

In using a telenovela for health communication purposes, there are many production aspects a health communicator must be aware of and address. First, they must understand and acknowledge the type of telenovela that will be best received in the culture they are working in. Some countries prefer humor over drama and vice versa. Next, communicators must effectively build their characters and use them to create melodrama to tell their story. Finally, health communicators must remember that their programing must remain a source of entertainment to the audience and they should refrain from being too forceful with their health information; it must be shared naturally through the story and characters.

Due to its one-way communication, the parents wanting more details or with new questions about clefts after viewing the television spots were left on their own to seek out these answers. So while television messaging impeded the sense-making process in that detail was not provided in full, it did prompt parents to continue their search and moved the sense-making process forward. Health communicators should recognize this need for more specific information and not only work to answer common parental questions in their programming, such as causes for clefts and patient requirements for surgery, but also provide a resource for parents to turn to for more information. This resource could be a medical professional, an organizational website, or any other information channel deemed appropriate for use in the target audience. By giving a next step, the sense-making process is guided toward accurate information rather than whatever the parent happens to find next.

Internet

The internet was not a common channel used to find information about clefts by the parents studied, so in most cases it neither helped nor impeded the sense-making process. Only four of those interviewed and nine that completed the survey stated they used it for that purpose. Of particular note when discussing its usage is the surprising statistics that one-third of respondents did not know what the internet was. Not just that they did not have it, but they had never heard of it and therefore were unable to answer the question pertaining to information from it.

Of those that described their internet usage in the interviews, each turned to the channel for a different type of information. Interestingly, the type of information they wanted and found fell into the original three categories of questions; what cleft is, how to care for the child, and what organizations can fix it. Although possible, due to distance traveled by some to access it, it is likely that the internet was not the first channel accessed by parents following the diagnosis, denoting a need for material to fill holes in information from medical professionals or another channel or to reinforce information already obtained. Three of the four parents were able to find information that they found helpful on the internet, having their sense-making process aided by finding answers to lingering questions unanswered elsewhere. One mother found no information of use and thus made no progress on her sense-making search, demonstrating that along with access, an individual needs technology skills and knowledge of how to use the internet in order for its content to be beneficial. Unfortunately, these skills may prove to be sparse in certain developing country settings.

While it was acknowledged that the internet would not provide the most exact information, the ability to search for exactly what one wanted to know outweighed the possible limitations on accuracy. In fact, internet users found the channel to be a more informative source than medical professionals when it came to clefts than non-users. This highlights the benefits of being able to tailor searches to specific individual informational needs and the ability to do so quickly on one's own time, eliminating time wasted waiting for an appointment with a medical professional. Survey results, however, counter patterns seen in interview narratives.

Survey results showed that internet users found the channel rather uninformative and hard to understand when it came to researching clefts. Overall, it received the lowest level of channel credibility as a health information resource, most likely due to the population's unfamiliarity with the channel. However, again, the ability to search for specific information and control one's own navigation through the channel may have appealed to users and cancelled out any negative attributes among users, demonstrated by 74.4% of Peruvian internet users stating they used it to obtain information (Zeta de Pozo, 2009). The internet allowed parents to take an active role in their child's healthcare (Rice, 2006), providing a needed feeling of control or power in their sense-making process.

Internet use may have also been perceived as a way to negate the influence of geography on information retrieval. By accessing the internet, even in instances where travel to a nearby town was necessary to connect, parents were able to reach outside of their rural communities for information from experts in larger cities or even different countries. For parents that did not feel asking friends and family for information was appropriate or a good use of time, the internet is a quick way to find support.

While results demonstrate that the internet should not be the preferred communication channel to reach parents of children with clefts in rural Peru, its use must be acknowledged because more than three-quarter of Peruvians use it at least once a week (Zeta de Pozo, 2009). By including a website address for a local health center or a visiting aid organization on or in messages from other communication channels, health communicators can direct inquisitive parents to internet resources that have accurate information, rather than allowing them to stumble upon random sites. Though this inclusion will not directly answer their questions, the guidance of the sense-making process toward helpful information will make information seeking for internet using parents much easier and may encourage more to do so. Additionally, by utilizing the internet as a channel for those who seek to use it, information can be bookmarked, printed, or shared easily, making the previously discussed information sharing role of friends and family more productive.

Radio

For the parents interviewed, the radio brought information of an upcoming mission, information on an event most had only heard would happen at some point. The announcement of specific dates presented a potential end to their child's cleft and this part of their sense-making journey, even if they still had unanswered questions about clefts. As with television, parents were provided with information allowing them to finally fix their child. Results, however, demonstrate that the radio is being underutilized for the dissemination of information about clefts in this Peruvian population, where many come from remote areas where access to television, the internet, and at times medical professionals is limited. Only three of the parents interviewed learned something from the radio, while almost half of those surveyed tried to use it to gather information on clefts. So for many, it was a wasted venture and unhelpful to the sense-making process.

Using the radio to gather health information is common in remote areas such as Juliaca and its surrounding cities. Although commonly used as an entertainment oriented media (Dutta-Bergman, 2004), for many in remote settings, the radio is both a source of entertainment and information. In Peru, 72% of homes had a radio in 2007, capturing a larger audience than any other media format (Zeta de Pozo, 2009). Listening to daily radio programs is a common practice, one that was created and still used to maintain their culture (Kreuter & McClure, 2004). In Huamanga, a province home to many indigenous cultures in Peru, radio programing has become extremely popular. Community members not only broadcast the daily news, but weekly programs to share and promote culture and tradition with younger generations (Chirapaq, 2012). Programming is done in their own ingenuous language and has become a point of pride for many involved in its broadcasting, as well as for those who listen.

With the demonstrated incorporation of radio programming in this population’s culture and others like it, health communicators could reach a large population with information about clefts through this method of communicating. While using the radio to expand the geographic reach of messages with information about surgical missions would and should be a top priority, the messages should also provide information about clefts in general due to their prevalence in these communities. Beyond mission advertisements, specific programs about health could feature information on clefts, reaching active and passive audiences. By bringing in doctors, parents of children with clefts, or individuals who have or had a cleft to share medical information and their personal stories the occurrence of clefts would not be as mysterious to parents or society as whole, thus lessening the fear and guilt that comes with a diagnosis. Use of shared narrative is supported by Fisher’s (1984) that people are natural storytellers. It would also provide the desired network for parents to share what they learned with others, providing the moral support that so many wanted.

Cleft information could also be worked into broadcasts of fictional audionovela programming, similarly to the telenovelas previously discussed and reaping the same benefits of mass public education. A successful example of using radio programming in this manner is that of *Rosa’s Story*, an audionovela about a young Hispanic woman living with diabetes. The narrative follows her from diagnosis through treatment and details her struggles and the support she received from her family (Joslin Dibetes Center, 2013). In essence, it is a fictional depiction of her sense-making process. Through programming like this, both fictional and non, cleft information can be consumed by large audiences, again increasing the awareness of clefts in general, shifting the public’s perceptions of them, and providing the previously discussed resulting benefits.

Clearly cultural practices support the use of radio for the dissemination of health information, but statistical results also showed that the information obtained from the channel is perceived as highly credible, coming in third of the channels studied, only slightly behind television. This may signal the benefit of visual aid use when sharing health information about a disfigurement or malformation in the media. Surprisingly health information from the radio was deemed more credible than information from friends and family, a channel used at only a slightly higher rate to gather information on clefts.

The high reliance on and credibility of information from the radio demonstrate a great need for improvement in health messages regarding clefts in order for them to have the greatest impact possible and the most influence on parental sense-making processes. Although commonly used to find information on clefts, many users found it to be the least informative source of cleft information, with fewer saying it was most informative. Additionally, more people found it the hardest source to understand than the easiest. To address such issues, attention should be paid to the language and literacy levels of those in the target population. As demonstrated in the interviews, many of the parent's seeking surgery for their child at the Juliaca mission did not speak Spanish. They expressed difficulty in communicating with physicians and turning to non-expert channels of communication because the shared language made it easier to communicate even if it lessened the quality of information. For these reasons, use of local radio will benefit health communicators. Not only can health issues that directly impact he community be discussed, but by broadcasting in local indigenous languages, information will be easier for audiences to understand and process, increasing the impact of radio efforts.

Newspapers

Used by none of the interview participants and only eight of the survey respondents, newspapers were the most unpopular channel for information seeking about clefts following a child's diagnosis. This was a surprising finding because newspapers are a reliable and accurate source of health information (Dutta-Bergman, 2004), but may be attributed to low literacy levels within the population. In none of the instances when newspapers were used to learn about clefts were they labeled as the most or least informative, or the easiest or hardest to understand. In fact, almost all newspaper users found television, radio or medical professionals to be most informative. This allows the conclusion to be drawn that newspapers were a non-impactful communication channel for the studied population and were not helpful in the parents' sense-making processes.

The lack of benefits found by parents in using newspapers to find information about clefts provides health communicators with an opportunity to improve their utilization of this communication method. Newspapers are a great way of communicating with audiences in developing nations and have proven useful in increasing knowledge, behavior change and self-efficacy in health related situations (Peltzer & Promtussananon, 2003). All of which would prove beneficial in the parental population studied. The parents perceived newspapers as moderately credible, ranking them fourth when compared to other channels. Of note is the ranking of the credibility of health information from newspapers above that from friends and family and the internet, both channels used more than newspapers. If local newspapers, 61 of which circulate in various Peruvian provinces outside of the capital city (Zeta de Pozo, 2009), were used to regularly provide accurate health information to a community, drawing upon expert knowledge from local health service providers or aid organizations, usage rates for the channel would increase as would knowledge and awareness about clefts. Another benefit would be the reception of information by more than just the target audience. Members of both the expert and lay communication channels would learn in the same way as the parents and thus be able to have the congruency of meaning discussed earlier (Maher, 1999).

Another way newspapers could be used by health communicators or organizations like Operation Smile that want to promote their services as well as aid the sense-making process of parents would be to publish stories about recent surgical missions. Within these stories, individual patient and/or parent narratives can be shared along with factual information about clefts and their treatments. By doing so, both the informational needs of parents as well as the expressed desire to share stories and information can be achieved. Because it is a printed media, pictures can also be used to show clefts before and after surgery, answering many of the secondary questions parents had. The visual aid would also help to lessen the impact low literacy levels had on information reception. Finally, use of newspapers would allow parents to have a hard copy of the information to save and use for future reference (Dutta-Bergman, 2004). Parents could then take the newspaper clipping to the doctor with them for more information, or use it as the basis for conversations with friends and family or internet searches.

Multichannel Use

While trends can be seen in the utilization of most individual communication channels studied, their roles in the sense-making process of parents following a cleft diagnosis, and opportunities for improving the use of each to aid that process put forward, the reality is that parents, once receiving a cleft diagnosis for their child, turned to multiple communication channels for information at the same time. Parents want as much information as possible in a very short amount of time, but due to unfamiliarity with clefts and low education and literacy levels they have difficulty evaluating the accuracy of message content, making the channel and format of message delivery even more important. The key to this research lies in understanding the use of multiple communication channels at the same time, how the uses and perceptions of information from each can influence the information-seeking process, and the cultural influences on health beliefs and media consumption within the studied population. It is up to health communication practitioners to decide how to utilize each channel in combination with others to achieve optimal outcomes.

With no attention paid to content, in several instances use of a specific channel influenced the use of others when searching for information on clefts. First, a positive correlation between television and radio use may indicate a tendency by the studied population to use mass media to gather health information, a behavior that should be explored further to determine if it is due to the ease of access over other channels, content, or simply part of their regular media use activities. Interestingly, however, both radio and television users found television easiest to understand; highlighting a possible opportunity to adjust radio content and delivery formats to match that of television.

Although not a useful channel in the information search, a slight positive correlation was found between newspapers users and the one respondent that stated using an “Other” channel to obtain information about clefts. While it is not provable, because the other source was listed as “Operation Smile,” it is logical to assume that it may have been a newspaper ad for the organization or mission that directed the parent’s information seeking behavior at the organization. While this demonstrates the possibility of a directional influence on the sense-making process, more importantly it shows an opportunity to use newspapers to guide information seeking behaviors that health communicators should take advantage of. If newspapers do serve as a successful referral channel of sorts to parents searching for information, content in placed advertisements for aid organizations should contain specific details on the mission as well as directions to other information resources where more content can be found. With an understanding of what types of information parents want to make sense of the diagnosis, in addition to details on mission dates, times, and patient requirements, newspapers can direct parents to a cleft organization website or specific health care facilities that can provide it, thus helping to facilitate the sense-making process.

Negative correlations were also found in information seeking behaviors for sense-making purposes, the first being between the use of friends and family for information about clefts and the internet. While this may be in part to limited internet access, it strongly supports the role of interpersonal connections when health issues are at hand (Greenhalgh et al., 1998). Rated the two least credible channels for health information, the additional emotional support received from friends and family when compared to the internet may have given it the edge for utilization. A second negative correlation was observed between medical professionals and those using an “Other” channel. Again, while only one parent noted using an additional channel, this relationship shows the value in answers from medical professionals and their ability to reduce the need for information seeking outside of the expert channel.

In addition to use of one channel influencing use of another for cleft research, relationships between the use of a specific channel for finding information on clefts and the overall credibility assigned to health information from other channels were found. Because knowledge of subject matter can impact credibility (Eastin, 2001), it is unclear if successes and failures of an information search impacted credibility or if perceived credibility influenced what communication channels were utilized for cleft information seeking. Either way, results provide support for designing health communication campaigns or programs that use multiple channels to reach a population and the importance of using each to support and reinforce information obtained from others.

The use of radio for gathering health information on clefts showed an impact on the perceived credibility of both interpersonal channels examined. Those that used the radio to find cleft information found general health information from friends and family less credible than those who did not use the radio. The same was true for general information from medical professionals. While results showing a lessening of credibility of information from medical professionals were unexpected, they demonstrate the important role radio plays in these communities. Parents that listen to the radio daily and visit the doctor seldom are going to pay more attention to information from the channel they are accustomed to. Because radio is a common entertainment channel (Dutta-Begman, 2004) and very popular in Peru, the lessening of credibility of information from friends and family may be due to parental beliefs that their interpersonal connections are simply repeating information they already heard on the radio and not providing new content.

Parents that turned to their friends and family for information found information from newspapers more credible than those who did not use the interpersonal network. As previously explained, newspapers often provided specific dates and locations for surgical missions, reinforcing the notion shared by many friends and family members that a mission would occur at some point. Because the specifics provided by the newspaper supported information from interpersonal channels and allowed parents to finally have the opportunity to fix their child, their higher level of credibility attributed to newspaper information among users of friends and family is reasonable. The same relationship with the credibility of information from medical professionals was observed within parents that turned to friends and family for information. Those that used the channel found health information from expert interpersonal channels more credible than those that did not reach out to lay interpersonal channels. This may be due to the reinforcement of ideas between the channels or the ability for both emotional and informational needs to be met when both channels were accessed following a diagnosis. If friends and family could be turned to for moral support, wanting and receiving only factual health information from medical professionals would become more acceptable and highly valued because additional needs would not need to be met by this expert channel.

Recommendations for Communicating with the Studied Population

Findings on the influence of culture and channel credibility provide understanding of attitudinal and behavioral aspects of the sense-making process of parents that receive a cleft diagnosis for their child in the Juliaca region of Peru. By evaluating these behaviors and the motivations behind them, health communicators can better reach these parents of children with clefts, assisting them through their initial sense-making journey. This assistance and guidance can be provided in many ways, evident from the conclusions drawn from this research. In order to have the greatest impact possible, health communicators need to address who their audience is and how to effectively reach them using multiple communication channels.

While it may seem obvious that the target audience of messages to assist in a sense-making process would be those going through the process, in the case of parents of children with clefts in rural Peru, reaching other audiences may be just as important. Due to a lack of complete and accurate information, medical professionals were found to be vital segment of the population that would benefit from information about clefts. Increasing the knowledge of medical professionals about clefts would have the ability to impact the sense-making process of every parent that received a diagnosis. Efforts should be made to design quality materials and trainings to increase Peruvian medical professionals' understanding of clefts, how to care for a child with one, and how to answer other common questions parents may have during their sense-making journey. Because they were deemed the most credible and informative, if medical professionals had the ability to answer all of the initial questions parents had, less effort could be spent on information seeking and more time could be dedicated to properly caring for their child. Aid organizations should also keep practitioners up to date on when medical missions will be in their region so they can then refer parents to them, information that most parents wanted from their doctor. Reversely, medical professionals may also be able to provide aid organizations with lists of potential patients to contact when they are holding a mission close by.

A second possibility for health communication practitioners to assist parental sense making in Peru is through raising awareness of clefts in the general public. Consequently, information available to the general public would also be available to parents, thus meeting two health communication needs at once. The culture of Latin America is largely the product of the mass media (Barbero, 1993). Therefore, using popular methods of mass media entertainment, like informational radio programming or tele- and audionovelas, basic knowledge of clefts would become mainstream, or at minimum, the condition would be recognized by more people as commonly occurring in their community. Clefts would no longer be seen as scary and misperceptions of their causes could be clarified, shifting cultural beliefs, and creating a more accepting society. Popular culture would begin to see clefts as parents do, as a flaw, not a handicap (Johansson & Ringsberg, 2004). With an increased understanding of clefts in the general public, notions of shame, blame and stigma associated with clefts can be reduced, allowing these babies to be seen as normal and parents not to be blamed for their child's condition. Reducing these ways of thinking would also allow for educated extended interpersonal networks to be built within a community that are better able to support these parents because they understand clefts. This places a strong responsibility on the mass media to disseminate accurate health information because of its clear ability to impact the culture, including beliefs and behaviors, of receiving audiences.

By reaching out to a mass audience with educational programming, the sense-making process of parents would benefit in several ways. By being introduced to clefts through a non-pressure media interaction, with plenty of time to process and store the information, parents will have a general knowledge of clefts to draw on if and when they receive a diagnosis. Additionally, upon receiving the diagnosis, emotions of fear or guilt will be alleviated to an extent because parents will have heard of or seen a cleft at some point and realize they were not the cause. Some of their initial questions may even be able to be answered using the knowledge generated from mass media exposure. Finally, parents can model their behaviors on those they had observed as successful, whether they are those of an actual parent or a fictitious one. As supported by Social Cognitive Theory, modeling based on observational learning can lead to increased self-efficacy (Rosenstock, Strecher, & Becker, 1988), which is crucial when parents are serving as caregivers for their child with cleft. In essence, instead of resorting to similar steps that may have helped them bridge a gap in the past (Savolainen, 2006), they will resort to using the steps that helped others.

In addition to deciding what audience will benefit the most from communication about clefts and will have the greatest impact on the sense-making process of individual parents, health communicators must also decide how to reach them. While efforts directed at medical professionals are easier to select channels for, those aimed specifically at parents or the general Peruvian public are harder to select. Results of this study lead to the conclusion that messages about clefts should target both active and passive information seekers in order to change overall cultural beliefs about clefts as well as influence parental sense-making behaviors and processes. By laying this foundation, educated medical professionals can then fill in the remaining informational gaps for parents when the need arises.

Television and radio proved to be the most popular mass communication channels in disseminating information about clefts to parents in Peru. Their use had implications for educating larger publics and their high levels of channel credibility make them logical choices for utilization. While high credibility may not equate directly to action or behavior change, it does increase the likelihood of message reception and knowledge creates that may lead to action at some point. It is important however, that because television and radio are the two most used channels for information seeking that they both provide the same accurate information so parents do not have to evaluate conflicting information. Through utilizing each channel in a fashion that audiences, both passive and active, are used to consuming, information on clefts will have the greatest chance for acceptance.

Research findings on cultural practices and attributed credibility of the studied population suggest communication strategies that will have the greatest impact. Television should be utilized to disseminate cleft information, taking advantage of the ability to reach lower literacy populations through visual information sharing methods. Of particular impact would be the sharing of personal narratives through fictional telenovela programming. Whether the appearance of a cleft was involved in a single episode or a series long plotline, the impact on Peruvian culture would be noticeable.

Currently, informational radio programing in local Peruvian dialects and indigenous languages is successful at reaching indigenous populations and should be used more for health purposes. Broadcasting to this public in local dialects would be particularly easy because radio programs in the region delivered in Quechua already outnumber those in Spanish (Unseco, 1971). In additional to informational programming, radio should take advantage of the fictional story telling capabilities of television to attract larger audiences. Use of communication channels and languages commonly utilized by the target population is supported by Communication Accommodation Theory (Giles, Coupland & Coupland, 1991) and increases the likelihood of message acceptance. By matching messages and channels used to audience attitudes and contexts, an increase in perceived credibility will be achieved, as well as better information recall (Wathen & Burkell, 2002).

Educating mass audiences through the use of edutainment, or the use of entertainment formats for educational purposes, over multiple communication channels to influence cultural perceptions and behaviors regarding a health issue have proven successful, as have educational programs in Peru that utilize both television and radio. In the health field, the Soul City program in South Africa to increase HIV/AIDS awareness and promote healthy behaviors successfully utilized multiple mass communication channels, including a soap opera, to reach their goals (Peltzer & Promtussananon, 2003). In the studied region of Peru, *Telescuela Popular Americana* (TEPA) successfully used a partnership between television and radio to provide basic elementary education to adolescents and adults (Unseco, 1971).

With primary education efforts focused on these two communication channels, health communicators should use newspapers predominantly for mission announcement and information referral purposes within this population. While an aid or community health organization should maintain an accurate website that can be referred to, the internet should not be the focus of communication efforts with the studied population. Health communicators should however periodically monitor media and internet consumption behaviors with in the studied population and be prepared to adjust their strategies when necessary.

Implication for Practitioners

It has been stated several times that it is difficult to generalize results from Sense-making studies beyond the study population due to high levels of subjectivity. There are, however, several takeaways from a sense-making study of this type that can be used by health communication practitioners, particularly those working in developing countries.

First, this study demonstrates the need for formative research within any population health communicators want to target. It is vital that practitioners understand not only what a population knows about a given health topic, but what they want to know. It is also important to understand the information seeking behaviors of individuals, as well as their perceptions of the information they obtain. The current examination of the influences of culture and channel credibility on attitudes and channel selection are two of many ways to understand the sense-making process and information seeking behaviors of a given population.

Next, this research demonstrates the possibility that parents or the individual affected by the disease or condition may not be the only appropriate audience to target with information. In the cases studied, information from medical practitioners was often limited or incomplete. After conducting formative research it may be found that health communication materials directed at medical professionals or other opinion leaders in the community would have a greater impact on the population than would radio or television programming or hard copy print messages aimed at the individual. Using a Sense-making framework, even if it is in conjunction with another health communication theory, will allow practitioners to see where the gaps in information lie and how best to fill them.

Finally, current research shows the importance of and opportunities for health communicators to reach both active and passive information seekers with their messages, especially in settings where culture plays an important role in health. Particularly in the health field, by introducing audiences to new health conditions or behaviors before they have a need to gather information about them, health communicators have the ability to provide a starting point or point of reference for future sense-making processes and guide the direction of information seeking behaviors. Potentially it could eliminate the need for some information seeking behaviors altogether. The appeal to the general public also provides the opportunity to shift cultural beliefs and stigmas about an issue, influencing the emotions associated with a particular diagnosis and impacting the situation and manner in which an individual approaches their initial informational gaps.

Theoretical Implications

While the core tenants and process posited by Sense-making Theory are supported by this research, results demonstrating the influence of culture on the sense-making process challenge the notion that results are too subjective and therefore not generalizable beyond the studied population. While the individualistic nature of each parent's sense-making process is clear, derived recommendations to use telenovela or radio programing formats to educate large populations about clefts or any other health issue are applicable to locations outside of Peru that share media consumption behaviors. Therefore results are able to be generalized beyond the studied population, negating previous theoretical claims. Additionally, the types of questions each parent had about their baby after diagnosis, those regarding specifics about the condition, how to care for their child, and how to fix it, may be generalized to other parents receiving different medical diagnoses for their children, particularly other unanticipated birth defects. Health communicators can use results of sense-making studies like this one to anticipate what type of information parents will want, thus making them better prepared to assist the parents on their sense-making journey. By using a common characteristic or informational gap to reach beyond the studied group, the subjectivity of results is preserved, however, theoretical boundaries are crossed and new value and utility is assigned to Sense-making Theory and its applications.

Study Limitations

As with all research, this study has its limitations. First, although interview numbers were comparable to other Sense-making studies, the number of survey participants was low due to the small size of turnout at the Juliaca mission site, impacting the statistical tests that could be used. While this limited possible findings, results accurately depicted the experiences, thoughts, and behaviors of the population being studied. While low numbers may be attributed to advertising methods used to recruit patients or the smaller size of the city selected by Operation Smile for the mission, it is of note that cultural beliefs about clefts may have also influenced who attended the mission to receive care for their child and thus could be recruited for participation. Parents that viewed their child’s cleft as a punishment for something they did may have decided not to seek help because they believe they should live with the consequences. These beliefs and decisions directly impact the sense-making process of this select group of parents and are important to understand; however, results examining the sense-making process of those who chose not to come to the mission are not represented in the findings of the current study, creating a sampling bias.

Language served as a limitation during both phases of data collection. During the interview phase, many participants spoke the local indigenous language of Quechua instead of Spanish. This provided difficulties in translating questions and answers to and from both English and Spanish that compounded the traditional limitations of having to use a translator. During the survey phase of the study, low levels of literacy combined with the language difference necessitated the unanticipated use of translators, which may again be perceived as a limitation for data collection.

In both data collection phases, the use of self-report methodologies is a limitation. While it was made clear that responses were anonymous and parents should be truthful, there was no way to prevent deception or untruthfulness in responses. Recall bias is another limitation of both data collection stages. Both the interviews and the survey asked participants to discuss past experiences, emotions, and behaviors. However, as previously discussed, when those experiences are major life events they are easier to recall in detail (Johansson & Rinsberg, 2004), thus reducing the impact of this limitation. Additionally, while not seen as a negative limitation from the Sense-making perspective, the lack of generalizability outside of the study population does limit the current research.

Additionally, by investigating communication channel credibility as a health information resource, the impact of source credibility for that information was not addressed. Finally, in neither phase of data collection were participants asked about their media consumption behaviors in general. While these omissions were justified by the research questions being asked, they provide opportunities for future research.

Future Research

Future research opportunities in this area are infinite. While this study examined the initial sense-making process upon diagnosis for parents in Juliaca, Peru, results demonstrated the creation of new sense-making cycles in both the parents and their children that deserve attention. Sense-making research involving the medical professionals or friends and family members used to gather information would provide insights on how each group perceives clefts, why they shared or provided the information they did, and where additional information gaps lie. An in-depth look at the actual communication channels and media materials disseminated with in the studied population would provide understanding as to the amount and type of information provided to parents versus what was is remembered and interpreted as useful. Finally, each channel studied provides opportunity to study information sources and their perceived credibility.

Outside of the current study, findings warrant the implementation of similar research in other populations health communicators wish to target. Whether that research be in a population of cleft parents from another country or with a population of parents or individual patients experiencing a different disease or condition altogether, Sense-making has proved to be a useful framework for understanding health attitudes and information seeking behaviors than can be used to improve health communication efforts.

CHAPTER 7

CONCLUSION

While the single sense-making process initiated at the point of diagnosis for many parents may be complete because enough information was obtained to build a bridge to cross the initial gap or the gap was skipped all together, it is crucial to understand that the cyclical process of sense making as a whole is never truly over. For parents of children with clefts, the diagnosis is the beginning of a sense-making journey that will last a lifetime. Even after initial questions from the diagnosis and secondary questions stemming from interactions with selected communication channels are answered and multiple rounds of sense making are complete, a new one begins the moment the child wakes up from surgery. Parents must now adjust to having a new child, with new facial features, an adjustment that can bring both positive and negative emotions (Rey-Bellet & Hohlfeld, 2004) and new questions, such as the one asked by Angelica regarding when her child could go back to school. Parents must also make sense of the potential need for a second surgery or years of speech therapy even though their child looks normal. The importance for each and any other aspect of comprehensive cleft care beyond the initial surgery is important to communicate early in the sense-making process so parents prioritize these extra services as part of the “fix” they desperately wanted at the time of diagnosis and not optional services post-surgery.

Each stage of cleft diagnosis, surgery, and follow-up care creates a new situation, with new gaps, and new bridges that must be built; all deserving of individual study.

These processes, however, are not limited to the parents. Medical professionals, individuals in the community, and the cleft patients themselves will all go through a sense-making journey. As Jacquline shared, one day she will have to explain clefts to her son. He will begin his own sense-making process to understand his condition and the continual care he receives long past surgery. It is vital that parents have a strong understanding of clefts before their child's sense-making process begins because the strongest predictor for adolescent adjustment to a cleft is maternal adjustment (Mednick et al., 2012).

The initiation of the child's sense-making process then put parents in a new cleft situation, creating a new sense-making cycle for them and their child to travel through together. The normalization of clefts into society through the sharing of factual, personal, and fictional stories using mass communication channel programming will aid the sense-making progress of all parties consuming the media formats, making it an easier and faster process as time passes and clefts become a more commonly known and accepted diagnosis.

Information and conclusions from this study can be used to improve health communication practices regarding clefts with parents in and around Juliaca, Peru, but perhaps the bigger impact will be on the practices of health communication practitioners in developing countries. By understanding the sense making process and its role in health information-seeking and behaviors, efforts can be made by health communicators to improve the information-seeking experience and accelerate message acceptance and behavior change or adoption. By conducting formative research through a sense-making lens before the design and implementation of a health communication campaign or program, gaps and barriers to information may be uncovered that may have been previously missed. Through understanding the aspects of a target population's culture that influence health beliefs and behaviors, the credibility assigned to health information from various channels, and the influence both have on channel selection, information can be disseminated to the target audience, the population as a whole, as well as any other audience deemed necessary to assist parents through the sense-making process.

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APPENDICES

Appendix A: Interview Consent Form (English)

I, _________________________ agree to participate in a research study titled “Parental Sense Making of Cleft Lip and Palates” conducted by Dr. Jeff Springston and Victoria Carter of the Grady College of Journalism & Mass Communication at the University of Georgia in the United States. I understand that my participation is voluntary and should take no more than 60 minutes. I understand that my interview will be audio recorded, transcribed and the recordings will be kept for one year in a secure location before being destroyed.

I can refuse to participate or stop taking part at any time without giving any reason, and without penalty or loss of benefits to which I am otherwise entitled. I can ask that the audio recording be immediately stopped and the audio file erased.

The reason for this interview is to examine the experiences and communication behaviors of parents of children born with cleft lip and palates. The study examines not only the sense making process, but also the communicaion channels used in it with hopes of making recommendations to improve health communication practices aimed at parents of children with clefts.

I understand to participate in this study I must be the mother or father of a child with a cleft lip or palate receiving surgery. If I volunteer to take part in this study, I will be asked to do the following:

1) Complete an interview with a researcher and translator about how I collected information on cleft lip and palates after I found out my child had one and the process I went through to make sense of it.

The researcher hopes to learn about the communication needs of parents of children with clefts and use this knowledge to improve health communication practices following diagnosis. The benefits to me are that I may help improve the health services available to myself and my community.

No risk or discomfort is expected. No information that can be identified as mine or provided by me during the research will be shared with others. Only members of the research team will have access to the information I provide in my interview.

The investigator will answer any questions about the research, now or during the course of the project.

I understand that I am agreeing by my signature on this form to take part in this research project and understand that I will receive a signed copy of this consent form for my records.

Researchers: Dr. Jeffrey Springston, jspring@uga.edu 1-706-542-7833 and Victoria Carter, vmc@uga.edu

Signature: ___________________________ Date _________

Name of participant: _____________________________

Signature: ___________________________ Date: _________

Please sign both copies, keep one and return one to the researcher. Additional questions or problems regarding your rights as a research participant should be addressed to the Institutional Review Board, University of Georgia, 629 Boyd Graduate Studies Research Center, Athens, GA 30602-7411; Telephone 706 542-3199; email IRB@UGA.edu.

Appendix B: Forma de Consentimiento para la Entrevista

Yo, ____________________, estoy de acuerdo para participar en este studio titulado "Parental Sense Making of Cleft Lip and Palates" realizado por Profesor Jeff Springston y Victoria Carter de la Universidad de Georgia Collegio Grady de Periodismo y Communicacion. Yo entiendo que mi participacion es voluntario y no debe tomar mas que 60 minutos. Entiendo que mi entrevista sera grabada con audio, transcrita y la grabracion se matendran por un ano en un lugar segura antes de ser destruidos.

Yo puedo negar participar o parar la intrevista en cualquier momento sin dar una razon o sin penal o sin sanción o pérdida de beneficios a los cuales tengo derecho. Puedo pedir que mi audio sea parado imediatamente y que el audio sea borrado.

La razon de esta investigacion es para examinar las experiencias y el comportamiento de communicacion de los padres de ninos nacidos con lapios leporinos y paladares. Esta investigacion no solo el processo de entender la situacion pero tambien los medios de communicacion utilizados en el con la esperanza de hacer recommendacinoes para mejorar las practices de communicacion en salud dirigidos a los padres de ninos con hendiduras.

Entiendo que para participar en este estudio tengo que ser madre or padre de un nino con labio leporino o paladar hendido que esta recuperando de una cirugia. Si me ofrezco como voluntario para este estudio, voy ser pedido que haga lo siguiente:

1) Completar una entrevista con un invetiagado y traductor de como collecte la informacion de ninos/a con labios leporinos y paladares despues que conoci que mi hijo/a tenia uno y el processo que use para entender que estaba pasando.

Los investigadores esperan aprender de las necessidades de informacion de los padres de ninos/a con labios leporinos y usar esta informacion para mejorar las practices de communicacion en salud despues del diagnostico. Los beneficios para me es que me puede ayudar a mejorar los servicios de salud disponibles para mi y mi communidad.

No se espera riesgo o molestia. La informacion que puede ser identificada o que fue previsto por usted en el curso de esta investigacion no vay estar compartido con otros. Solo los miembros de la investigacion van a tener accesso a la informacion que esta compartida en la entrevista.

El investigador respondera a cualquier pregunta sobre la investigacion, ahorra o en el curso de el proyecto.

Yo entiendo que estoy de acuerdo que mi firma en este formulario para participar en esta investigacion y entiendo que voy a recibir una copia firmada de este formulario para mis registros.

Investigador: Dr. Jeffrey Springston, jspring@uga.edu 1-706-542-7833 y Victoria Carter, vmc@uga.edu

Firma: ___________________________ Fecha: _________

Nombre de participante: _____________________________

Firma: ___________________________ Fecha: _________

Por favor firme las dos copias de este formulario y regreselo a la investigadora. Otras preguntas o problemas acerca de sus derechos como participante en la investigacion debe dirigirse a la Junta de Revision Institucional, University of Georgia, 629 Boyd Graduate Studies Research Center, Athens, GA 30602-7411; Telephone 706 542-3199; email IRB@UGA.edu.

Appendix C: Interview Guide with Spanish Translation

Note: Interviews will be conducted with the help of a translator that has been familiarized with the study and the questions being asked.

Buenos días,

Good Morning,

Mi nombre es Victoria Carter, soy una estudiante de doctorado en la Universidad de Georgia en los Estados Unidos. También soy una ex-empleada de Operación Sonrisa y estoy trabajando con ellos en un proyecto para mi universidad.

My name is Victoria Carter and I am a PhD student at the University of Georgia in the United Sates. I am a former Operation Smile employee and am now working with them on a research project for school.

Agradezco el tiempo que me da al conversar conmigo.. Este estudio se lleva a cabo para poder entender mejor el proceso por el que usted pasó cuando supo que su bebé tenía un labio leporino y/o paladar hendido. Me interesa saber cómo recopiló información y cómo la usó para entender la condición de su hijo/a. Quiero subrayar que sus respuestas son todas válidas. Es decir, no hay respuestas incorrectas. Yo estoy interesada en sus ideas y opiniones sinceras, sean estas positivas o negativas, sobre su experiencia de ser el padre/madre de un niño con labio leporino o paladar hendido.

I appreciate you taking time to talk with me today. This study is being conducted to better understand the process you went through when you learned your baby had a cleft lip and/or palate, how you collected information and used it to make sense of your child's cleft condition. I want to underscore that all answers are valid. There are no wrong answers to the questions; I am simply interested in your honest thoughts and opinions, both positive and negative, about your experiences as a parent of a child with a cleft lip and/or palate.

Usted puede decidir no responder cualquiera de mis preguntas, también puede acabar la entrevista cuando quiera. Tiene total libertad. Esta entrevista será grabada. Y, al participar en la entrevista, usted aprueba también ser grabado. Para fines de la investigacion las entrevistas van a ser transcritas. Su información personal no aparecerá en el reporte final, así que sus opiniones e ideas son confidenciales. Nuestra conversacion va a durar entre 30 y 45 minutos. ¿Le parece bien?

You may choose not to respond to any question that I ask, and you may end the interview at any time. In that sense, you are completely free. The inverview will be taped, and by participating in it, you agree to be taped. This is for research purposes only – the interviews will be transcribed, and no personally identifying information will be used in *the reporting of our findings. Our conversation should last about 30-45 minutes. Is that all OK with you?*

AT THIS POINT CONFIRM THAT THE CONSENT FORM HAS BEEN EXPLAINED, SIGNED AND ALL QUESTIONS ARE ANSWERED

Bien, vamos a empezar.

Great, let's get started.

¿Usted es la madre/el padre de una niña o niño con labio leporino y/o paladar hendido, correcto?

You are the mother/father of a child with a cleft lip and/or palate, correct?

¿Me puede contar del momento en que supo que su hijo/a tiene labio leporino?

Can you please tell me about when you first learned your child had a cleft?

¿Cuándo fue? ¿Cómo se sintió?

When was it? How did you feel?

¿Qué preguntas tenia al respecto? ¿Qué tipo de batalla interna tuvo?

What questions did you have? What did you struggle with?

En aquel momento, ¿qué clase de información o qué tipo de ayuda necesitaba usted?

At that time, what kind of information or help did you want?

¿Dónde busco esa información?

Where did you go to get it?

¿Qué tipo de ayuda necesitaba?

What type of help did you need?

¿Dónde encontró esa ayuda?

Where did you go to get it?

Note: The following questions will be repeated for each person/source the interviewee states they went to for help or information:

¿Por qué fue a _________ buscando información/ayuda?

Why did you go to ___________ for information/help?

¿Qué aprendio de esa persona/Qué aprendió en ese lugar?

What did you learn from he/she/it?

¿Le fue útil esa información? ¿Por qué si o por qué no?

Was this information helpful? Why or why not?

¿Le dieron alguna información que usted sintió que era inútil o no lo ayudaba?

Did they tell you anything that you felt was unhelpful or useless?

¿Qué le faltó?

What was missing?

¿Tuvo problemas encontrando información/ayuda en ________? ¿Qué hizo?

Did you have any problems getting information/help from ___________? What did you do?

¿Cómo se sintió después de recibir la información?

How did you feel after receiving the information?

¿Qué preguntas nuevas se le ocurrieron?

What new questions did you have?

******* *Probes of "Can you tell me more?" "Is there anything else?" "Can you give more detail?" may be used to follow up any of the questions above.*

**** ¿Me puede decir más? ¿Hay algo más? ¿Me puede dar más detalles?

Esas son todas las preguntas que tengo para usted hoy. ¿Hay algo más que le gustaría compartir que piensa que ayudará con este proyecto?

Well, those are all the question I have for you today. Is there anything else you would like to share that you think would help this project?

Gracias por su participación. Si tiene otras preguntas, puede encontrar la información para contactar al investigador principal en la forma que firmó al principio de la entrevista. Por favor no dude en contactarnos. Que tenga un buen día. Y, de nuevo, muchas gracias.

Ok, well thank you again for participating. If you have any other questions, contact information for the lead researcher is provided on the consent form, so please feel free to contact us. Have a great day, and, again, thanks.

Appendix D: Survey Consent Form

I, _________________________ agree to participate in a research study titled “Parental Sense Making of Cleft Lip and Palates” conducted by Dr. Jeff Springston and Victoria Carter of the Grady College of Journalism & Mass Communication at the University of Georgia in the United States. I understand that my participation is voluntary and should take no more than 20 minutes. I can refuse to participate or stop taking part at any time without giving any reason and without penalty or loss of benefits to which I am otherwise entitled. I can choose to take my survey with me if I decide not to participate.

The reason for this survey is to examine the experiences and communication behaviors of parents of children born with cleft lip and palates. The study examines not only the sense making process, but also the communicaion channels used in it with hopes of making recommendations to improve health communication practices aimed at parents of children with clefts.

I understand that participation in no way influences the medical team’s selection of surgical candidates.

I understand to participate in this study I must be the mother or father of a child with a cleft lip or palate. If I volunteer to take part in this study, I will be asked to do the following:

> 1) Complete a written survey regarding communication channels I used to collect information on clefts, as well as my opinions on the credibility of health information from each channel. I will also answer questions about my and my child’s demographics—age, education, gender.

The researchers hope to learn about the communication needs of parents of children with clefts and use this knowledge to improve health communication practices following diagnosis. The benefits to me are that I may help improve the health services available to myself and my community.

No risk or discomfort is expected. No information that can be identified as mine or provided by me during the research will be shared with others. Only members of the research team will have access to the information I provide in my survey.

The investigator will answer any questions about the research, now or during the course of the project.

I understand that I am agreeing by my signature on this form to take part in this research project and understand that I will receive a signed copy of this consent form for my records.

Researchers: Dr. Jeffrey Springston, jspring@uga.edu 1-706-542-7833 and Victoria Carter, vmc@uga.edu

Signature: ___________________________ Date _________

Name of participant: _____________________________

Signature: ___________________________ Date: _________

Please sign both copies, keep one and return one to the researcher. Additional questions or problems regarding your rights as a research participant should be addressed to the Institutional Review Board, University of Georgia, 629 Boyd Graduate Studies Research Center, Athens, GA 30602-7411; Telephone 706 542-3199; email IRB@UGA.edu.

Appendix E: Forma de Consentimiento para la Encuesta

Yo, ____________________, estoy de acuerdo para participar en este studio titulado "Parental Sense Making of Cleft Lip and Palates" realizado por Profesor Jeff Springston y Victoria Carter de la Universidad de Georgia Collegio Grady de Periodismo y Communicacion. Yo entiendo que mi participacion es voluntaria y no debe tomar mas de 20 minutos. Yo puedo negar participar o parar la intrevista en cualquier momento sin dar una razon o sin penal o sin sanción o pérdida de beneficios a los cuales tengo derecho. Si decido no participar puedo elegir llevar mi encuesta conmigo.

La razon de esta investigacion es para examinar las experiencias y el comportamiento de communicacion de los padres de ninos nacidos con lapios leporinos y paladares. Esta investigacion no solo el processo de entender la situacion pero tambien los medios de communicacion utilizados en el con la esperanza de hacer recommendacinoes para mejorar las practices de communicacion en salud dirigidos a los padres de ninos con hendiduras.

Entiendo que para participar en este estudio tengo que ser madre o padre de un nino con labio leporino o paladar hendido. Yo entiendo que participacion no ejerce una influencia en la seleccion de candidatos para la cirugia en el equipo medico.
Si me ofrezco como voluntario para este estudio, voy ser pedido que haga lo siguiente:

1) Completir una encuesta escrita con respecto a los canales de communicacion que se utilizan para recopilar informacion sobre las grietas, y mis opinions sobre la credibilidad de la informacion de salud de cada cana de communication. Tabien voy a dar respuestas sobre la demografia de mi y mi nino/a – edad, educacion y sexo.

Los investigadores esperan aprender de las necessidades de informacion de los padres de ninos/a con labios leporinos y usar esta informacion para mejorar las practices de communicacion en salud despues del diagnostico. Los beneficios para me es que me puede ayudar a mejorar los servicios de salud disponibles para mi y mi communidad.

No se espera riesgo o molestia. La informacion que puede ser identificada o que fue previsto por usted en el curso de esta investigacion no vay estar compartido con otros. Solo los miembros de la investigacion van a tener accesso a la informacion que esta compartida en la encuestra escrita.

El investigador respondera a cualquier pregunta sobre la investigacion, ahorra o en el curso de el proyecto.

Yo entiendo que estoy de acuerdo que mi firma en este formulario para participar en esta investigacion y entiendo que voy a recibir una copia firmada de este formulario para mis registros.

Investigadors: Dr. Jeffrey Springston, jspring@uga.edu 1-706-542-7833 y Victoria Carter, vmc@uag.edu

Firma: ___________________________ Fecha: _________

Nombre de participante: _____________________________

Firma: ___________________________ Fecha: _________

Por favor firme las dos copias de este formulario y regreselo a la investigadora. Otras preguntas o problemas acerca de sus derechos como participante en la investigacion debe dirigirse a la Junta de Revision Institucional, University of Georgia, 629 Boyd Graduate Studies Research Center, Athens, GA 30602-7411; Telephone 706 542-3199; email IRB@UGA.edu.

Appexdix F: Survey

Thank you for taking time to complete this survey. Please answer the following questions based on your experience once finding out your child had a cleft lip and/or palate. Please be as honest as possible. Your answers will be kept confidential.

What did you use to learn more about clefts and how to care for your child? Check all that apply

___ Television
___ Newspapers
___ Radio
___ Internet
___ Friends and Family
___ Medic Professionals
___ I don’t know
___ Other:
____

Of the media you used, what was the most helpful source of information about clefts and how to care for your child? Check one.

___ Television
___ Newspapers
___ Radio
___ Internet
___ Friends and Family
___ Medic Professionals
___ I don’t know
___ Other:
____

Of the media you used, what was the least helpful source of information about clefts and how to care for your child? Check one.

___ Television
___ Newspapers
___ Radio
___ Internet
___ Friends and Family
___ Medic Professionals
___ I don’t know
___ Other:
____

Of the media you used, which provided the easiest to understand**?** Check one.

___ Television
___ Newspapers
___ Radio
___ Internet
___ Friends and Family
___ Medic Professionals
___ I don’t know
___ Other:
____

Of the media you used, which was the hardest to understand? Check one.

___ Television
___ Newspapers
___ Radio
___ Internet
___ Friends and Family
___ Medic Professionals
___ I don’t know
___ Other:
____

Please answer the following questions based on your personal opinions of health information coming from the specified source. Circle the number or response the best fits your opinion. Numbers 1 and 5 indicate a very strong level of agreement or disagreement. Numbers 2 and 4 indicate a normal level of agreement or disagreement. Number 3 indicates a neutral level or that you do not agree or disagree.

Health information on **television** is:

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Accurate	1	2	3	4	5
Believable	1	2	3	4	5
Trustworthy	1	2	3	4	5
Informative	1	2	3	4	5
Convincing	1	2	3	4	5

Health information on the **radio** is:

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Accurate	1	2	3	4	5
Believable	1	2	3	4	5
Trustworthy	1	2	3	4	5
Informative	1	2	3	4	5
Convincing	1	2	3	4	5

Health information on **the internet** is:

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Accurate	1	2	3	4	5
Believable	1	2	3	4	5
Trustworthy	1	2	3	4	5
Informative	1	2	3	4	5
Convincing	1	2	3	4	5

Health information in **newspapers** is:

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Accurate	1	2	3	4	5
Believable	1	2	3	4	5
Trustworthy	1	2	3	4	5
Informative	1	2	3	4	5
Convincing	1	2	3	4	5

Health information from **friends and family** is:

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Accurate	1	2	3	4	5
Believable	1	2	3	4	5
Trustworthy	1	2	3	4	5
Informative	1	2	3	4	5
Convincing	1	2	3	4	5

Health information from **health professionals** (doctors, nurses, therapists) is:

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Accurate	1	2	3	4	5
Believable	1	2	3	4	5
Trustworthy	1	2	3	4	5
Informative	1	2	3	4	5
Convincing	1	2	3	4	5

Please answer the following questions about yourself:

Are you the child’s ____Mother _____Father ____Other Please explain: _______

Your Age: _____ Your child with a cleft’s age: _________

What is your highest level of education? Check one.
____ No High School
____ Some High School
____ High School
____ University

When did you find out your baby had a cleft? _____ Before the baby was born
_____ After the baby was born

Does anyone else in your family have a cleft lip or palate? _____ Yes
_____ No

Appendix G: Encuesta

Gracias por el tiempo que me da al completar esta encuesta. Por favor responda las siguientes preguntas basada en su experiencia desde que supo que su hijo o hija tiene un labio leporino o paladar hendido. Por favor sea honesto, sus respuestas serán confidenciales.

¿ Qué medios usaste para aprender sobre labio leporino y sobre cómo cuidar a su hijo? Marque todas las que apliquen.

___Televisión
___Periódicos
___Radio
___Internet
___Amigos y Familia
___Profesionales Médicos
___ No sé
___ Otro:
____

¿De todas los medios de communicación que ha usado, cuál fue el más informativo acerca del tema de labio leporino y del cuidado de su hijo/a? Marque uno.

___Televisión
___Periódicos
___Radio
___Internet
___Amigos y Familia
___Profesionales Médicos
___ No sé
___ Otro:
____

¿De todos los medios de comunicación que ha usado, cuál fue el menos informativo acerca del tema de labio leporino y del cuidado de su hijo/a? Marque uno.

___Televisión
___Periódicos
___Radio
___Internet
___Amigos y Familia
___Profesionales Médicos
___ No sé
___ Otro:
____

¿De todos los medios de communicación que ha usado, cuál fue el más fácil de usar y entender? Marque uno.

___Televisión
___Periódicos
___Radio
___Internet
___Amigos y Familia
___Profesionales Médicos
___ No sé
___ Otro:
____

¿De todos los medios de communicación que ha usado, cuál fue el más difícil de usar y entender? Marque uno.

___Televisión
___Periódicos
___Radio
___Internet
___Amigos y Familia
___Profesionales Médicos
___ No sé
___ Otro:
____

Por favor conteste las siguiente preguntas basándose en sus opiniones personales sobre la informacion sobre salud que usted encuentra en fuentes específicas. Marque el numero o respuesta que representa su opinión. El número 1 indica un alto nivel de desacuerdo. El número 2 indica que usted está en desacuerdo. El número 3 es neutral: usted no está ni de acuerdo, ni en desacuerdo. El número 4 indica que usted está de acuerdo. El número 5 indica un alto nivel de acuerdo.

La información de salud que hay en **la televisión** es:

	Muy en desacuerdo	No está de acuerdo	Neutral	De acuerdo	Muy de acuerdo
Exacta	1	2	3	4	5
Creíble	1	2	3	4	5
Digna de confianza	1	2	3	4	5
Informativa	1	2	3	4	5
Convincente	1	2	3	4	5

La información de salud que hay en la **radio** es:

	Muy en desacuerdo	No está de acuerdo	Neutral	De acuerdo	Muy de acuerdo
Exacta	1	2	3	4	5
Creíble	1	2	3	4	5
Digna de confianza	1	2	3	4	5
Informativa	1	2	3	4	5
Convincente	1	2	3	4	5

La información de salud que hay en **Internet** es:

	Muy en desacuerdo	No está de acuerdo	Neutral	De acuerdo	Muy de acuerdo
Exacta	1	2	3	4	5
Creíble	1	2	3	4	5
Digna de confianza	1	2	3	4	5
Informativa	1	2	3	4	5
Convincente	1	2	3	4	5

La información de salud que hay en **los periódicos** es:

	Muy en desacuerdo	No está de acuerdo	Neutral	De acuerdo	Muy de acuerdo
Exacta	1	2	3	4	5
Creíble	1	2	3	4	5
Digna de confianza	1	2	3	4	5
Informativa	1	2	3	4	5
Convincente	1	2	3	4	5

La información de salud que me dan los **amigos y la familia** es:

	Muy en desacuerdo	No está de acuerdo	Neutral	De acuerdo	Muy de acuerdo
Exacta	1	2	3	4	5
Creíble	1	2	3	4	5
Digna de confianza	1	2	3	4	5
Informativa	1	2	3	4	5
Convincente	1	2	3	4	5

La información de salud que me dan los **profesionales médicos** es:

	Muy en desacuerdo	No está de acuerdo	Neutral	De acuerdo	Muy de acuerdo
Exacta	1	2	3	4	5
Creíble	1	2	3	4	5
Digna de confianza	1	2	3	4	5
Informativa	1	2	3	4	5
Convincente	1	2	3	4	5

Por favor conteste las siguiente preguntas:

Yo soy ___ Madre ___Padre de la niña/niño ___Otro, por favor explique: ___________

Su edad ______ La edad de su niña/niño con el labio leporino o paladar hendido ______

Su nivel de educación. Marque uno.
____ Educación primaria
____ Algo de educación secundaria
____ Educación secundaria
____ Educación universitaria

¿Cuándo se enteró que su hijo/a tiene labio leporino o paladar hendido?
____ Antes de su nacimiento _____ Después de su nacimiento

¿Hay alguien más en su familia que tenga un labio leporino o paladar hendido?
_____ Sí _____ No