

DEPRESSIVE SYMPTOMS AMONG CULTURALLY DEAF ADULTS

by

Kate G Sheppard

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As members of the Dissertation Committee, we certify that we have read the dissertation prepared by Kate G Sheppard entitled "Depressive Symptoms Among Culturally Deaf Adults" and recommend that it be accepted as fulfilling the dissertation requirement for the Degree of Doctor of Philosophy

Terry A Badger, PhD, RN, FAAN Date: March 11, 2008

Cathleen L Michaels, PhD, RN, FAAN Date: March 11, 2008

Elaine G Jones, PhD, RN Date: March 11, 2008

Marylyn Morris McEwen, PhD, APRN, BC Date: March 11, 2008

Final approval and acceptance of this dissertation is contingent upon the candidate's submission of the final copies of the dissertation to the Graduate College.

I hereby certify that I have read this dissertation prepared under my direction and recommend that it be accepted as fulfilling the dissertation requirement.

Dissertation Director: Terry A Badger, PhD, RN, FAAN Date: March 11, 2008

STATEMENT BY AUTHOR

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SIGNED: Kate G. Sheppard

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ABSTRACT

Aims were to describe depressive symptoms among culturally Deaf adults, describe the words in American Sign Language (ASL) that best express depressive symptoms, and describe shared meaning of depressive symptoms. Primary care providers commonly discuss depressive symptoms with clients, which can lead to earlier identification of those at risk for depression. However, providers may not discuss depressive symptoms with Deaf clients due to communication barriers. Health care providers are rarely familiar with ASL, and depression screening tools are not easily translated from English to ASL. There has been no investigation about Deaf adult's experiences with depressive symptoms or the signs used to describe those experiences.

The study method employed hermeneutic interviews and analysis. Nine culturally Deaf adults were interviewed three times each, and certified interpreters were used to assist with ASL communication. After reviewing each interview with the interpreter for accuracy of translation, text was generated through word-for-word transcription and researcher observations; text was then read to obtain a broad understanding of the experience.

Findings: Symptoms described by Deaf adults paralleled those of hearing adults. Four shared meanings emerged: 1) Feeling depressed, defined as the physical and emotional manifestations of depression and the ASL signs and phrases used to communicate these; 2) Emotional chaos leading to depression, defined as experiences of childhood, adolescence, and adulthood that led to feelings of depression such as feeling different, feeling isolated from family and peers, feeling excluded, and feeling limited by

others; 3) Reaching out, defined as learning to walk in the Deaf world while also navigating the hearing world; 4) I am Deaf – I am not broken!

Conclusions: This research provided a description of depressive symptoms as may occur among culturally Deaf adults, which may lead to increased understanding of depression as experienced by and expressed by members of the Deaf culture. In this way, improved communication and understanding between health care providers and Deaf adults can be optimized. Such knowledge may potentiate the earlier identification of culturally Deaf adults at risk for depression in the primary care setting, thereby reducing morbidity and mortality in this underserved population.

CHAPTER I: INTRODUCTION

Depression is the greatest cause of non-fatal burden socially and economically, worldwide (Schotte, Van Den Bossche, De Doncker, & Cosyns, 2006); it is the most common mental health disorder, affecting millions of people annually. In the primary care setting it is estimated that 13 to 25% of patients are seeking care for depressive symptoms, and 80% of those actually treated for depressive symptoms had previously seen their primary care provider (Manning, Clements, & Friedman, n.d.). As described in the literature, the term *depression* may connote a clinical diagnosis but is also used to describe an emotional experience. For some, depressive feelings may be a temporary reaction to an event or situation. For others, depressive symptoms or feelings are deeper and may last longer (Johnson & Roberts, 1996). Symptoms of depression may cause physical, emotional, or cognitive manifestations of mood alteration that interferes with everyday life over time. Failing to discuss depressive symptoms increases the risk of missing signs of clinical depression and even suicide (Murray et al., 2006). In this study depressive symptoms refer to physical, emotional, or cognitive manifestations of mood alteration that interferes with everyday life over time.

Background

Primary care providers such as advance practice nurses (APNs) may be the initial point of contact for individuals experiencing depressive symptoms. APNs and physicians commonly discuss depressive symptoms with their clients (Fraguas et al., 2006; Tylee, 1999), which can lead to earlier identification of those at risk for depression. Many health care providers even manage depression or depressive symptoms in the primary care

setting, thereby reducing morbidity and mortality (Belnap et al., 2006). However, primary care providers often fail to discuss depressive symptoms with their culturally Deaf clients (Tamascar et al., 2000) in part because they are not adequately trained to discuss or assess depressive symptoms among culturally Deaf adults (Montoya et al., 2004).

While researchers have historically defined deaf individuals as having a disability, most culturally Deaf adults see themselves as members of a unique, non-disabled culture. Culture is defined as a given group with a common language, unique values, beliefs, and practices (Kim Godwin, Clarke, & Barton, 2001). Culturally Deaf adults are those who lost their hearing at an early age, often prelingually (before the onset of speech development), who prefer to communicate in the visual language of American Sign Language (ASL), and who self-identify as members of the Deaf community (connoted by upper case 'D'). Members of the Deaf culture have a common knowledge and a collective memory that is used to communicate; this way of knowing is learned and shared over time, and guides thinking, behavior, and decisions in a common way (Stebnicki & Coeling, 1999). The uniqueness of the Deaf culture must be considered in any physical or mental aspect of the primary health care assessment.

Approximately 15% of people in the U.S. are deaf or hard of hearing (4.5 million) and 38% of those who lost their hearing before the age of 19 are pre-lingually deaf (approximately 600,000) (Ries, 1994); despite the significant prevalence of deafness, culturally Deaf adults are statistically under-represented in the epidemiological studies of depression. We can anticipate that 90,000-150,000 culturally Deaf adults are experiencing depressive symptoms that significantly disrupt their daily lives, but the

literature illustrates that a minimal number of culturally Deaf adults are actually identified in primary care as experiencing such symptoms. There is no evidence in the literature to suggest that culturally Deaf adults do not experience depressive symptoms, but methods of assessing depressive symptoms among the population are unreliable and inadequate for the primary care setting. Most studies exploring depressive symptoms among culturally Deaf adults are quantitative in nature, and fail to capture the overall experience of the phenomenon from an insider's perspective. This qualitative study will explore the phenomenon of depressive symptoms in the words and experiences of individuals within the Deaf culture.

Statement of the Problem

Healthy People 2000 and *2010*, a comprehensive national incentive for health promotion and disease prevention, specifically identified culturally Deaf adults as having inequitable mental and physical healthcare due to barriers in communication (Chang, 2001), thus increasing vulnerability and the associated risk of illness. Culturally Deaf adults often leave the primary care setting without having discussed any depressive symptoms with their provider (DeVinney & Murphy, 2002; Pollard & Adams, 2004) and may leave feeling frustrated, discouraged, and believing that care has been substandard (Barnett, 2002). Differences in communication, culture, and linguistics between health care providers and culturally Deaf adults often lead to misinterpretation, misdiagnosis and stereotyping (Steinberg, Wiggins, Barmada, & Sullivan, 2002). As depressive symptoms among culturally Deaf adults are frequently missed (Roberts & Hindley, 1999), it is estimated that only 2% of culturally Deaf adults ever receive the mental health

care they need (Leigh & Pollard, 2003). Improved assessment of depressive symptoms and identification of those at risk for depression are critical priorities in health care, and designated by the National Institute of Mental Health (Jackson et al., 2004) as a high priority. Improvements in care must begin in the primary care setting with open dialogue and mutual understanding between providers and their culturally Deaf adult clients.

Depression screening tools used in primary care may be unreliable for culturally Deaf adults (Young, Tattersall, Uus, Bamford, & McCracken, 2004) because they have not been adequately translated and validated. Terms such as "depression" or "self-esteem" are not easily translated from English to American Sign Language (ASL) (Vernon & Miller, 2001). It is quite common to face language barriers and translation challenges in primary care, and efforts are frequently made to address the needs of Spanish, Hmong, Laotian, Russian, Cambodian, and Mandarin speakers. However, translating from English to ASL is different from translating from one spoken language to another (E. Jones, Mallinson, Phillips, & Kang, 2006) because it has the added complexity of going from the visual language of ASL to spoken English.

The *Diagnostic and Statistical Manual of Mental Disorders* (DSM) (American Psychiatric Association, 2000) description of clinical depression may be unreliable for the culturally Deaf population as it fails to adequately address the culture of the population (Lala, 1998); symptoms presented in text may be misrepresentative of depressive symptoms among culturally Deaf adults. The current DSM IV-TR (American Psychiatric Association, 2000) criteria for depression is inadequate for the culturally Deaf adult population (Lala, 1998), and it is doubtful that any Deaf adults or experts

collaborated in the development of the text. Terms that are used to discuss depressive symptoms must be modified for this population.

In order to identify culturally Deaf adults experiencing depressive symptoms, primary health care providers such as APNs need an enhanced understanding of how depressive symptoms might be described – not as determined by texts such as the DSM but by the population. This study addresses a major gap in the literature by describing depressive symptoms as experienced by culturally Deaf adults, and in the words and language used by the culture (ASL). These findings will enable the researcher to then develop a culturally sensitive and appropriate tool to assess depressive symptoms among culturally Deaf adults seen in primary care. Findings from this study will be shared with the culturally Deaf community through publications and presentations, and with those who provide care to culturally Deaf adults; this may enhance dialogue about depressive symptoms between primary care providers and culturally Deaf adults.

Purpose of the Study

The purpose of this study is to explore depressive symptoms as experienced by culturally Deaf adults. Specific aims include:

- ◆ Describe depressive symptoms among culturally Deaf adults seen in the primary care setting;
- ◆ Describe the ASL signs and phrases that express the Deaf adult's perspective of depressive symptoms;
- ◆ Describe the shared meaning of depressive symptoms among culturally Deaf adults. Shared meaning refers to commonalities within the experience of

depressive symptoms such as similar word use, phraseology, emotions, understanding, awareness, or physical responses.

Research Questions

Two questions guide this study:

- (1) How do culturally Deaf adults describe depressive symptoms?
- (2) What is the shared meaning of such symptoms?

Significance of the Study

Health care practitioners, especially those working in primary care settings are frequently the initial point of contact for patients experiencing depressive symptoms. Given the fact that in 1994, 4.5 million people in the United States were identified as profoundly deaf (Ries, 1994), it is entirely possible that health care practitioners could be in a position to provide primary care for culturally Deaf adult patients. This research will provide a description of depressive symptoms from the perspective of culturally Deaf adult individuals, as expressed in their native language (i.e., ASL). This will lead to increased understanding and meaning of the phenomenon as experienced by culturally Deaf adults.

The culture of the Deaf is centered on a unique language. This common means of visual communication and the common language (ASL) is their natural means of relating to the world (Lane & Bahan, 1998). Members of the culture are bound together by the experience of deafness, which offers a distinctly different perspective of the world (Dolnick, 1993; Padden & Humphries, 1988). The notion of a Deaf culture falls best within the ethnic or national culture paradigm (Sparrow, 2005). Members of the Deaf

culture do not believe that their deafness necessitates a cure, and most do not consider themselves as disabled or broken.

An imperative in culturally competent and holistic care is to understand each person's unique experience of illness, (Baker, 1997) which has historically been lacking in health care to members of the Deaf culture. This study will help primary care providers to discuss depressive symptoms with their culturally Deaf clients in words that are meaningful and culturally relevant to the population, thus increasing identification of culturally Deaf adult patients at risk for depression. The knowledge gained from this study can lead to development of a culturally sensitive and reliable instrument to assess depressive symptoms. Such knowledge may enable nursing to collaborate with other members of the research community to reduce the significant disparities in primary health care for culturally Deaf adults, thereby reducing morbidity and mortality in this underserved population.

Underlying Philosophy and Conceptual Perspectives

The study is guided by the philosophical underpinnings of hermeneutic phenomenology. The conceptual perspectives that inform this study include vulnerability, culture, and depression. The researcher assumes the belief that culturally Deaf adults are members of a unique culture. The literature review illustrates the uniqueness of the Deaf culture, defines its members as potentially vulnerable especially within the primary health care setting, and describes extant perspectives of depression with emphasis on psychosocial theories that may pertain to culturally Deaf adults.

Hermeneutic Phenomenology

The philosophy of hermeneutic phenomenology presumes a holistic perspective; human realities are complex, and comprised of cognitive, emotional, spiritual, and physical dimensions. Guided by this philosophy, the researcher seeks to understand the nature of the human experience, and language is the data that gives meaning to the experience. The philosophy stems from constructionism (Crotty, 2003); people construct meanings in relation to their world and their worldly experiences.

The general purpose of qualitative research is to explore, describe, illustrate, or conceptualize, a phenomenon. Aims are to disclose subjectivity, to learn or come to understand the view of another. A research imperative is to suspend one's own foundational beliefs and views in order to understand or know another's perspective. Qualitative researchers seek to understand a phenomenon from a way that may be different from their own. Qualitative research has tremendous applicability in health care, as the provider often has one way of viewing or interpreting, forming meaning, and making sense of things, while the client/patient frequently has a different way of viewing, understanding, and knowing.

The hermeneutic philosophy and methodology is a valuable research approach when little is known or understood about a phenomenon (Fleming, Gaidys, & Robb, 2003; Geanellos, 1998). Hermeneutic phenomenologists seek to elicit and describe perceptions, experiences, and meaning (Fleming et al., 2003). The research methodology provides an alternative to the traditional scientific model, and is especially useful when attempting to understand or describe an experience or phenomenon from a patient

perspective (Robertson-Malt, 1999). Language and understanding cannot be separated (Gadamer, 1975), and language is the traditional route to understanding.

Hermeneutic inquiry stems from the philosophy of Heidegger (1889-1976), and Gadamer (1900-2002) (Fleming et al., 2003); it is the Gadamerian philosophy that provides the underpinnings for this study. The postmodern tradition of hermeneutic interpretive phenomenology enables the researcher to expand awareness and gain an understanding of illness and treatment (Crogan, Schoenbaum, Sherbourne, & Koegel, 2006) in the words and meaning that best express an individual's perspective.

Hermeneutics fosters the skill of listening to the speaker and to the context/meaning of the expressed language (Annels, 1996). The method should be seen as separate and distinct from phenomenology, in which the researcher identifies and brackets pre-understanding (Priest, 2002). Through the interview, the researcher investigates the informant's experience of the world in order to describe the phenomenon, then analyze and interpret it. A hermeneutic interview differs from a traditional interview in that participants are viewed as experts that the researcher seeks to learn from (Turner, 2003; Van der Zalm & Bergum, 2000). Gadamer's (1975) perspective is that language is the medium which enables understanding; understanding thus necessitates language and occurs through interpretation. Using this method, the researcher initiates dialogue with an open-ended question. Although the researcher may have several prepared questions, the interview is co-created by the researcher and the participant. As the most legitimate expert on the phenomenon, the participant equally guides the direction of the interview. Ongoing reflection provides a coherent way to carry out analysis and to synthesize the

descriptions of the phenomenon (Fleming et al., 2003; Wiklund, Lindholm, & Lindstrom, 2002).

The Researcher's Reflection

As guided by the philosophy of hermeneutic phenomenology, the researcher identifies her pre-understanding or conscious awareness of the phenomenon under investigation. Such awareness stems from experiences, knowledge, beliefs, and values (Munhall, 2001). This researcher was raised in a very strict, maternally-dominated Irish Catholic household, which affected her choice of profession and her desire to listen to the stories of others; she holds a profound belief that every individual deserves to be heard. As an educator and experienced APN, she has had numerous encounters that certainly influence her understanding and interpretation. This researcher has provided primary health care for many culturally Deaf adults, and many adults experiencing symptoms of depression; rather than bracket or set aside her clinical knowledge and experience, she will identify these factors through continued reflection and journaling as they influence the process of analysis and interpretation.

When first taking coursework for the dissertation, the researcher had not really considered the different perspectives of deafness. As a lover of music, the sounds of laughter, and the sounds of nature, she presumed that given the option of deafness or full hearing, any individual would choose to hear. She also presumed that a deaf person would undergo a surgical procedure or consider cochlear implants if the hearing loss could be corrected. It was only after immersing herself in the literature regarding deafness and culture that she began to appreciate and understand the sense of pride Deaf

adults express toward their culture. However, throughout the interviewing process, she needed to be ever-mindful of her health care background and great appreciation for the sounds she hears daily, and consider how these may affect the interviews and interpretations.

This researcher is aware that the philosophical foundation for research may represent a choice of values – of people, knowledge, or politics. Metatheoretical coursework has allowed the researcher to formulate her personal worldview of health and nursing, which influences the research inquiry and choice of method. Her worldview is that person consists of mind, body, spirit, and emotions; these facets constantly interact with the environment, are composed of patterns that are created from one's life experiences, create perceptions of the present, and may provide hope for the future. The person is in constant interaction with their environment, and the direction of the interaction is unpredictable. Nursing is a caring engagement in another's health experience, a mutual interaction between patient and nurse. The nurse facilitates transcendence by fostering 'power to' through reflection, empathic listening and communication. Transformation occurs in the interpenetration of the client's and the nurse's patterns, which includes the client's concept of health and the nurse's theoretical understanding and experience. Ontologically, each is transformed by the mutual experience, and epistemologically each has come to a new way of knowing.

Summary

The impact of depressive symptoms can be life-altering; symptoms can severely disrupt one's daily life and can even lead to suicide. Fortunately for many who experience

such symptoms, resources are available. Unfortunately for culturally Deaf adults, similar resources are often difficult or even impossible to obtain. Extreme differences in communication and understanding between clients and health care providers impose daunting barriers. This study begins to bridge the gap in understanding by describing the symptoms, words, and meanings of depressive symptoms from a culturally Deaf adult's perspective. This chapter reviewed the problem statement, and identified the purpose, research questions, and the significance of the study. The underlying philosophy and conceptual perspectives that guide the study were described. Chapter II discusses the conceptual perspectives of culture, vulnerability, and depression, and illustrates the impact of each among culturally Deaf adults.

CHAPTER II: LITERATURE REVIEW

There is a paucity of literature describing depressive symptoms among culturally Deaf adults. Articles are available that describe the Deaf culture, how to use an American Sign Language (ASL) interpreter in health care settings, and how to conduct mental health therapy for culturally Deaf adults. There is, however, a dearth of information to help primary care providers discuss depressive symptoms with their Deaf clients or to understand how symptoms might be experienced by culturally Deaf adults. It is important to be able to discuss depressive symptoms with clients in order to distinguish normal emotions of sadness with mood alterations that interfere with daily living.

Chapter II contains a review of the literature that provides conceptual perspectives for this study. Deaf adults are described as either disabled or members of a unique culture, who are potentially vulnerable within the health care setting. The following literature review illustrates the difficulty in identifying culturally Deaf adult individuals with depressive symptoms. Conceptual perspectives that guide this study are reviewed within the literature, to include vulnerability, culture, and depression. Theories of depression are reviewed, with emphasis on theories that may pertain to Deaf adults.

Medical and Cultural Models of Deafness

There are two primary conceptual models of deafness: cultural and medical. Each model offers a different perspective for assessment, intervention, and the concept of self-identity. Table 1 highlights the significant differences between the medical and cultural model of deafness.

TABLE 1: Medical and Cultural Models of Deafness

Models of Deafness	Medical Model	Cultural Model
Definition of deaf	Absence of ability to hear; is a condition, disease, disability	Hearing loss at early age, self-identify as member of Deaf culture, communicate in ASL
Assumptions	Deafness as limitation Necessitates intervention Predisposed to psychological problems	Deaf as a trait or characteristic that does not need to be fixed; language (ASL) as inseparable component of culture
How connoted	Lower case "d" (deaf)	Upper case "D" (Deaf)
Who is guided by the model	Health care professionals, policy makers, those unfamiliar with deaf culture, those with later hearing loss	Those familiar with the culture, social network of family, friends, those who sign, and who mediate between cultures
Measurement	Decibels Frequency	Pure signer, learned to sign later in life, no sign communication
How categorized	By degree, etiology of hearing loss, by interventions	Prefer to communicate in ASL, consider this most natural and comfortable means, able to express self best in ASL
Hard-of-hearing	Easily accommodated in this model as to degree of loss	Not accommodated unless consider ASL as native language
Implications	Treatment options such as cochlear implants, hearing aides, listening devices	If no societal barriers and can access knowledge, there are no limitations on success
Rehabilitation	If correction not an option, then retraining (occupation) and teaching speech-reading, oral speech training	Reject idea of mainstreaming Resident schools seen as fostering the culture, history, heritage, language
Effect on health care	Deafness may be cured Child treated as sick	Distrust of culture toward health care providers, miscommunications, and stigmatization.
Effect of cochlear implants	Leads to mainstreaming and reduces expenses in society	Will lead to demise of culture

Medical Model of Deafness

The medical model is also called the pathological model or disease model of deafness (Table 1). The model is based on empirical science, and presumes that deafness is an illness or a disability. The emphasis is on hearing thresholds rather than the social

experience of deafness. Central concerns are the cause of the hearing loss, the extent of the loss, and the search for a cure or amelioration in order to use sound. Speech-reading and spoken English are seen as necessary components of communication. This view contends that people who can hear are classified as "the norm", and proposes that Deaf people deviate from that norm (Signmedia, 2006). The model reflects the most common view among health care providers, policy makers, many professionals, and those not familiar with the Deaf culture. Often people who lose hearing later in life align with this philosophy (Ladd & John, 1991). The model groups deaf and hard-of hearing together, the only distinction being the significance of hearing loss and the amount of correction possible (Woodward & Allen, 1993).

In the United States, one in every 1000 people are born profoundly deaf, and two to three per 1000 are born with partial hearing loss; hearing loss is the number one birth defect in America (Center for Disease Control, 2006). The use of the lower case "d" connotes deafness as a pathology (Dolnick, 1993). Hearing loss is evaluated by the extent and etiology of the loss, and the potential for treatment or correction.

The extent of hearing loss is assessed by frequency (Hertz or cycles per second; the higher the pitch, the higher the frequency) and decibels (DB, the unit of measurement of intensity used to assess hearing ability or loss) (Martin & Clark, 2000). Normal conversations generate approximately 60 DB. Hearing loss is categorized in the medical model as mild (25-40 DB, where soft sounds are hard to distinguish), moderate (40-60 DB, conversations are harder to hear, especially if background noise is present), moderately severe (61-75 DB; difficult to hear any conversational speech), severe (75-90

DB; conversational speech cannot be heard), and profound (above 90 DB; most sounds are inaudible) (CDC, 2006). The medical model is most concerned with responses to a set of acoustic signals that are interpreted as hearing (Martin & Clark, 2000).

The etiology of hearing loss is categorized as conductive, sensorineural, and mixed (i.e., a combination of conductive and sensorineural). Etiologies of conductive hearing loss (i.e., interference of transmission of sound from outer to inner ear) include chronic otitis media, otosclerosis, serous otitis, and trauma. Sensorineural (i.e., damage of pathway for sound impulses from hair follicles of inner ear to auditory nerve and brain) losses may be caused by genetics, Rh incompatibility, hypoxic birth, maternal rubella during 1st trimester, cytomegalovirus, neonates exposed to excessive noise during incubation, hyperthermia, certain viruses, and ototoxic medications such as gentamycin, quinine, and streptomycin (American Speech-Language-Hearing Association, 2004; Center for Disease Control, 2006; Martin & Clark, 2000). Approximately 50 to 75% of all childhood deafness stems from hereditary causes; 15 to 30% of hereditary deafness is syndromal in nature (CDC, 2006). Over 400 such syndromes have been identified. Penrod syndrome is the most common syndromal cause of deafness (approximately 4 to 10% of cases); this autosomal recessive disorder is accompanied by goiter and possible changes in thyroid function (CDC, 2006).

Deafness as Disability

Hearing loss is portrayed through the medical lens as a handicap and limitation in social, emotional, vocational, and psychological areas. The use of sound is seen as a necessity to quality of life, without which there is limited communication and

engagement with the environment (American Speech-Language-Hearing Association, 1992). Treating the hearing loss becomes the prime focus. Numerous personal hearing aide-devices and assistive hearing devices may be advocated by the provider and attempted by the client. Rehabilitation is often aimed at retraining, learning to speech-read, and speech training (Brueggemann, 1995).

Guided by the medical model, the provider sees justification for earlier intervention to diagnose and treat. Professionals aim to help deaf citizens become fully functional in the hearing world, and literate members of society. Deafness is seen as an individual experience that needs treatment. Providers often focus on the etiology of deafness (Barnett, 2002).

Cochlear Implants

Cochlear implants are increasingly common; approximately 25,000 people in the United States have implants, and almost half of those receiving implants are children under the age of two (Center for Disease Control, 2006; Sparrow, 2005). Medical proponents argue that cochlear implants will lead to earlier linguistic/communication skills. Implants are seen as a necessity for successful mainstreaming, and are proposed as less costly to society than residential schools for the Deaf (CDC, 2006).

Cultural advocates view reparative efforts such as cochlear implants and spoken English, speech training, speech-reading education as jeopardizing the normal development of the deaf child. Proponents contend that implants do not sufficiently remedy linguistic problems, as signed language is an equally valuable alternative form of communication (Lane & Bahan, 1998). Despite the best of intentions to "cure", cochlear

implants may remove the child from the Deaf culture and the opportunities membership affords (Sparrow, 2005). Implants are viewed by many culturally Deaf adults as cultural genocide (Levy, 2002a; Sparrow, 2005). Most deaf children are born to hearing parents (de Halleux, 2001), and these are children who would most likely receive cochlear implants; opponents to implants feel the choice is being made without regard to the effect on the Deaf culture and the ultimate demise of the culture (Levy, 2002a).

Assistive Devices

There have been many technological advances in recent years, and some devices have been developed specifically for deaf and hard-of-hearing individuals. Hearing aids are used by hard-of-hearing, and are even used by some profoundly Deaf adults to enhance what little sounds are available. Assistive listening devices are used with or without hearing aids, and may include personal frequency modulation systems (e.g., a speaker uses a transmitter, and listener uses a receiver that may be linked directly to the hearing aid). Induction loop systems may be used in larger group situations (e.g., a speaker talks into a microphone, then sound is relayed to the hearing aide) (American Speech-Language Association, 2008). Some Deaf adults use note-takers during class, and some children use sound field systems in the classroom. Computers have made communication easier for Deaf adults, with computer-assisted video calls and online chat rooms. Cellular telephones have enhanced communication for Deaf people, enabling them to communicate longer distance without the aid of a telephone relay operator.

Cultural Model of Deafness

Culture is defined as a group of people centered around a unique language, and having a commonality of interdependent values, beliefs, ways of knowing, traditions, and organizations (Baker, 1997). The culture shares and passes down art, history, poetry, and ways of disseminating information that helps to distinguish one group from another. Cultures can be identified by behaviors that resemble the given community, that are learned and culturally determined (Padden & Humphries, 1988). The uniqueness of the culture's language may render the culture a linguistic minority (de Halleux, 2001; Lane & Bahan, 1998). Table 1 further delineates the medical versus cultural model of deafness.

Diversity is not limited to ethnicity. The literature describes culturally Deaf adults as members of a distinct culture, with a unique language, ASL. Stebnicki and Coeling (1999) conducted a literature review of the Deaf culture using the Sunrise Model; they describe the culture as rich with heritage including historical events, famous figures, art, literature, and folklore, a common language, and a set of customs and value. The culture may include family, friends, and a social network of people who use sign, and may also include those who mediate between cultures such as interpreters and educators (Dolnick, 1993; Woodward & Allen, 1993).

The culture of the Deaf is centered on their unique language. This common means of visual communication is their natural means of relating to the world (Lane & Bahan, 1998). Deaf children gain more sense of cultural identity from their culturally deaf peers than from their hearing parents (Dolnick, 1993), and most Deaf adults have other Deaf adults as intimate or life partners. Members of the culture are bound together by the

experience of deafness, which offers a distinctly different perspective of the world (Dolnick, 1993; Padden & Humphries, 1988). The concept of a Deaf culture falls best within the ethnic or national culture paradigm (Sparrow, 2005). The cultural model offers a clear distinction between the hard-of-hearing or deaf who communicate with spoken English and those who self-identify as culturally Deaf and communicate visually.

The concept of a Deaf culture stems from deaf people themselves. Harlan Lane, a linguist and a hearing man, is considered to be the father of the Deaf culture movement (Dolnick, 1993). "Deafhood" is an emic perspective on the non-spoken language and visually oriented identity, and describes the Deaf experience through Deaf people, their history, and their culture (Research in Centre for Deaf Studies, 2006). It is a process of self-actualization in a social movement for social change; the term was first coined by Paddy Ladd, a British professor of Deaf Studies and a culturally Deaf adult (McDonald, 2006). It is seen as a unifying concept that considers the unique worldview, epistemologies, and ontologies of culturally Deaf adults, and which strongly opposes the negative schema of the medical model (Research in Centre for Deaf Studies, 2006). Deaf as culture was exemplified by the DPN (Deaf President Now) movement at Gallaudet in 1998, when culturally Deaf adults demonstrated their vision of selves, moving beyond the pathological model to be seen as a unique culture (Brueggemann, 1995).

Some researchers and even some members of the Deaf culture consider themselves as members of a linguistic minority. Language may be an inseparable aspect of cultural identity and heritage (M. Jones, 2002). ASL signifies group membership (Dolnick, 1993; M. Jones, 2002); ASL is a critical aspect of this unique culture, and any

perceived threat to the use of ASL is viewed as a threat to the culture itself (M. Jones, 2002). It is through ASL that expression of values, beliefs, traditions, history, humor, and arts are shared. ASL is considered to be the most natural language for deaf people, as it allows members to communicate without conscious effort (de Halleux, 2001), and has no written language tradition of its own.

Mitchell and Karchmer (2004) have investigated the experience of deaf children raised by hearing parents and deaf children raised by one or more culturally Deaf parents; the deaf child raised by Deaf parents is more apt to regularly sign at home, and the choice to sign at home is primarily a parental decision. Membership in the Deaf culture is not determined so much by the degree or nature of the hearing loss but by the ability to communicate in ASL (Lane & Bahan, 1998).

Proponents of the cultural model approach deafness as a trait or characteristic that does not compromise their quality of life. Rehabilitative efforts at learning to communicate in an alternate language are seen as devaluing the natural visual sign language (Brueggemann, 1995). The cultural model proposes that rather than being unable to interact with the environment, members have a heightened sense of awareness through sight, enhanced peripheral vision, and touch. The perception is that ASL is a perfectly legitimate method of communication, and culturally Deaf adults live full and rich lives without feeling a sense of loss (de Halleux, 2001; Ladd, 2005; Werngren-Elgstrom, Iwarsson, Elmstahl, & Dehlin, 2005). Their contention is that deafness is not a disability but is a state of being that does not necessitate medical diagnostics or intervention.

Deafness as a Choice

The conflict between the medical and cultural perspective of deafness is exemplified by a couple's efforts at artificial insemination. A culturally Deaf lesbian couple wanting to become pregnant created uproar in the medical community by seeking out a Deaf sperm donor whose etiology of deafness was genetic in nature. The action was seen by many members of the medical community as choosing a real limitation for their child and violating the child's right to an open future (Levy, 2002b). Members of the culturally Deaf community countered that the birth of a deaf child to deaf parents is cause for celebration (Dolnick, 1993; Sparrow, 2005). Deaf parents have been known to grieve after giving birth to a hearing child (de Halleux, 2001; Stebnicki & Coeling, 1999), as they anticipate that their child will not be a member of the Deaf culture (Ross & Feller, 2005). Culturally Deaf parents may even undergo genetic testing to see if the baby will be deaf (Sparrow, 2005), and do not feel that a deaf baby is a cause for concern.

Deafness as Strength

The cultural model of the Deaf views deafness as a natural occurrence. Deafness is seen as a trait that facilitates the most rapid entry into the culture, and needs no remedy (Dolnick, 1993; Ladd & John, 1991). A multiple case exploratory study with three deaf college students identified assets the students used to bridge the hearing world, such as humor, commitment to goals, strong social bonds, social authenticity, comfort with solitude, self-advocacy, self-reliant, and problem-solving skills (S. Rogers, Muir, & Evenson, 2003); the sample of college students is clearly not representative of the

culturally Deaf population but helps to illustrate some potentially mediating factors of vulnerability.

From an outsider's perspective, culturally Deaf adults might appear to be a vulnerable population. While researchers have traditionally explored deafness as a disability and often applied a medical model to research, more recent studies consider deafhood as a unique culture and describe it as strength through vulnerability. A review of the literature on the subject of vulnerability explores this further.

Vulnerability

Vulnerability is defined in the nursing literature as a lack of resources and an increase in risk to health, causing a decrease in health status and predisposing one to mental and physical illness. Vulnerability is described as being dynamic and contextual (A. Rogers, 1997), with an openness to circumstances that positively or negatively influence consequences or outcomes (Purdy, 2004). It is existential (Sveinsdottir & Rehnsfeldt, 2005) and is not quantifiable (Spiers, 2000). The two terms are often used interchangeably. In this study, the author and researcher further conceptualizes vulnerability as a state of being, and risk as a behavior.

Risks and Resources

In the mental health setting, risk may be seen as the increased likelihood of mental or psychiatric illness. Specific factors may place the individual at higher risk of developing psychiatric illness. For example, Charney and Manji (2004) demonstrated that early childhood stress and stressful life events increase the risk of depression. In the context of mental health, the provider can conduct a risk assessment as a routine part of

the health care encounter (Crowe & Carlyle, 2003) in order to ascertain risk of suicide, risk of depression, risk of substance abuse or dependence, and risk of post-traumatic stress disorder.

Authors offer different descriptions of resources. Resources may include income, education, marital status, social status, and group support (Flaskerud & Lee, 2001). Aday (2001) proposes that social ties, defined in her conceptual framework as individual resources (e.g., social status and human capital) and community resources (e.g., ties between people, within one's neighborhood, and the degree of social support) should be added to the list of critical resources. Nyamathi (1998) conducted a literature review and found that housing, employment, and income are often listed as critical resources. Personal characteristics of age, gender, ethnicity or minority status (Leeman, Harrell, & Funk, 2002), disability, and safety (Aday, 1994) may also be described as resources.

Vulnerability in non-nursing health care literature has similarities to the nursing construct; it is viewed as derived from multiple sources, is not dichotomous but continuous, and is socially influenced. Determinants of individual vulnerability include disparities within a social or geographic setting (Dever, Sciegaj, Wade, & Lofton, 1988), and lack of social justice may render individuals more vulnerable to even minor psychiatric illness (Elovainio, Kivimaki, & Vahtera, 2002). Emotional vulnerability is described in psychology as being independent of physical vulnerability (Basic Behavioral Science Task Force of the National Advisory Mental Health Council, 1996). Social cohesion is identified as a resource and may affect vulnerability and health, as people need a comparison group to normalize their experience (Elstad, 1998). Support from

families and community is a resource that is associated with more successful adaptation and favorable outcomes (MacElveen-Hoehn & Eyres, 1984).

Increased risk predisposes one to poor physical, psychological, and social health problems. Risk is associated with a higher prevalence of untreated illness (Badger, McNiece, & Gagan, 2003). Risks may be socially influenced, as in social interactions and risk taking. Risk is also described as a convergence of risks rather than one isolated risk factor (Shi, Forrest, von Schrader, & Ng, 2003). Risk may be categorized by levels (e.g., Type 1 can be controlled by the individual, Type 2 necessitates help from others, and Type 3 is beyond one's control or influence) (Sellman, 2005).

Vulnerable Populations

Researchers have traditionally described infants and children, elderly, females, minorities, single women, the uneducated, same-sex partners, and those with less income as vulnerable. The trend in vulnerable populations research has gone from focusing on ethnicity to examining psychosocial risk factors of health disparities (Flaskerud et al., 2002). Being of minority status is associated with depression and poorer perception of health, due to less resources (Flaskerud & Winslow, 1998). Leight (2003) conducted an exploration of rural populations using the theories of Aday (1994) and Flaskerud and Winslow (1998), and illustrated that members of rural populations may be vulnerable. The uninsured and those without regular health care are described as vulnerable (Shi & Stevens, 2005). While theories of vulnerability have stemmed from medical or epidemiological models, there is a need to approach the concept from a cultural

perspective (Spiers, 2000); when considering the cultural view, vulnerability is not seen as an inevitable outcome of resource depletion.

From an outsider's perspective, culturally Deaf adults are a vulnerable population. As a social group, they have limited resources, such as health education (Gilchrist, 2000; Harmer, 1999; Mallinson, 2004), health insurance (Harmer, 1999), lower income (Werngren-Elgstrom, Dehlin, & Iwarsson, 2003) and less human capital generated in part by a lower educational level (Bain, Scott, & Steinberg, 2004; Lock, 2003). There may be complicating health concerns, as 30% of congenitally deaf children have co-morbid physical disabilities (American Speech-Language-Hearing Association, 2004) and higher prevalence of mental health illness has been reported (Carvill, 2001; De Graaf & Bijl, 2002). Both Aday (2001) and Rogers (1997) identify at-risk individuals as those family members of an abusive household; culturally Deaf adults with co-morbid disability are at increased risk of physical and sexual abuse (MacDougall, 2000).

Vulnerability in the Health Care Setting

Culturally Deaf adults may be particularly vulnerable in the health care setting. Seeking health care may render culturally Deaf adults vulnerable to neglect, as evidenced by providers feeling discomfort toward their culturally Deaf patients and feeling unprepared to interact with these patients (Barnett, 2002; Cooper, Rose, & Mason, 2003; DeVinney & Murphy, 2002; Ebert & Heckerling, 1995). Culturally Deaf clients may have difficulty communicating with the health care team and system (Meador & Zazove, 2005; Osborne, 2003), which creates barriers to accessible health care (Chang, 2001). They are usually asked to communicate in a language beyond their own comfort level

(Ross & Feller, 2005; Ubido, Huntington, & Warburton, 2002), and as a result, often fear medication errors (Ross & Feller, 2005).

As described in the literature, the greatest challenge between health care providers and culturally Deaf adults is communication. Communication problems are not related to intelligence but in the uniqueness of ASL as a visual language that may not be readily translated into English. ASL differs from English both in grammatical form and in its sensory modality. Communicating in ASL is not simply a matter of changing the modality of a spoken/written language from oral or written modality to visual/signed modality. Rather, ASL is a distinct language with distinct grammar and syntax, and all the characteristics of a separate language. There is a clear distinction between those who use ASL and oral speakers (e.g., lip-read and voice). Lip reading or speech-reading necessitates English comprehension (Haskins, 2000), and many culturally Deaf adults do not speech-read. Likewise, not all deaf communicate in ASL, and not all are fluent in ASL (Carvill, 2001); it is imperative to consider the patient's level of education and communication preference during any health assessment (Brauer, Braden, Pollard, & Hardy-Braz, 1998; Committee on Disabilities of the Group for the Advancement of Psychiatry, 1997). There may also be a significant difference between deaf children who are schooled locally versus those who are sent away to residential schools (Glickman, 1986). Because there is a significant difference in English and ASL, culturally Deaf adults often show less aptitude and intelligence if examined in English than if examined in ASL (United States Department of Education, 2004).

Concepts may not be literally translated from spoken English to the visual language of ASL. In a comparison study (i.e., two focus groups comprised of prelingually deaf adults using ASL versus spoken English), it was noted that concepts of time and duration were difficult to translate, and methods of gaining attention such as banging on the floor, are commonly accepted among culturally Deaf adults CDA; this may lead to misdiagnosis if there is a lack of cultural awareness (Steinberg, Lipton, Eckhardt, Goldstein, & Sullivan, 1998a). Culturally Deaf high school graduates may only read and write English at a 5th grade level; therefore adult individuals often struggle with reading and writing English. This may lead to confusion and misunderstanding if health care providers are dependent upon written notes to communicate. Culturally Deaf adults have learned to nod assent to avoid embarrassment when a lack of understanding occurs (Roberts & Hindley, 1999). Facial expressions are often used to augment the meaning of an ASL sign or phrase, to emphasize a thought or feeling, or to convey varying intensity.

Vulnerability in Mental Health Care Settings

Culturally Deaf adults may be particularly vulnerable when seeking care for mental health concerns. The desire to seek mental health care has been described as moving out of the Deaf person's comfort zone (Cassidy, 2000) and may be stigmatizing (Cornes & Wiltshire, 1999) or extremely uncomfortable (Iezzoni, O'Day, Killeen, & Harker, 2004). Mental health resources may be severely lacking for culturally Deaf adults; few hearing mental health providers have the skill or expertise to assess or treat these patients (Brauer et al., 1998; Pollard & Adams, 2004; Steinberg, Sullivan, & Loew, 1998b). Two primary methods of assessing mental health problems are through

assessment screening tools and dialogue; communication barriers abound, and there is a dearth of reliable and meaningful instruments applicable for culturally Deaf adults (Connolly, Rose, & Austen, 2006; Haskins, 2000; P. Zazove, Meador, Aikens, Nease, & Gorenflo, 2005).

The difference in perspective may cause conflict or communication difficulties between the provider and patient if the provider views the patient as disabled and the patient's self-perception is that of belonging to a cultural or linguistic minority. Health care providers frequently treat culturally Deaf adults as disabled (McLeod & Bently, 1996). This conflict can create confusion, misunderstanding, resentment, frustration, lack of understanding, and ultimately lead culturally Deaf clients to refrain from seeking health care altogether. The medical model perpetuates the illusion that deafness may be temporary or curable (de Halleux, 2001). The deaf child often grows up being constantly poked, prodded, evaluated, and is treated as a sick person rather than a healthy one.

Seeing culturally Deaf adult clients may challenge health care providers beyond merely diagnosis and intervention. Differences in communication, culture, and linguistics between health care providers and culturally Deaf adults lead to misinterpretation, misdiagnosis and stereotyping (Steinberg et al., 2002). Culturally Deaf adults often leave the primary care setting without having discussed their symptoms or health concerns with their provider (DeVinney & Murphy, 2002; Pollard & Adams, 2004) and may leave feeling frustrated, discouraged, and believing that care has been substandard. Self-perception of health care was explored among Culturally Deaf adults (N=87) and hearing (N=88) clients; the culturally Deaf experienced greater misunderstanding and greater

discomfort (P. Zazove et al., 1993). Culturally Deaf adults often express feelings of embarrassment or shame in the health care setting (Ubido et al., 2002). Rather than listening to the central concerns of the individual, the provider may focus on the etiology and course of deafness, and the client may leave the health care setting without ever having their concern addressed (Briffa, 1999; Gilchrist, 2000).

As the number of clients with depressive symptoms has increased significantly over the years, many health providers are now discussing, identifying, assessing, and managing symptoms in the primary care setting (American Psychiatric Association, 2000; Sheppard, 2006). Culturally Deaf adults are, however, rarely asked about depressive symptoms by their primary care provider (Tamascar et al., 2000), and fewer treatment options are presented and discussed (DeVinney & Murphy, 2002). Culturally Deaf adults have been labeled as psychotic when using ASL in health care settings (Briffa, 1999). Lack of assessment skills appropriate for culturally Deaf adults, and failures in communication and understanding lead to numerous missed cases of depression (Pollard, 1996; Roberts & Hindley, 1999) and inhibits conversations about depressive symptoms. These difficulties account for some of the disparities in health care to culturally Deaf adults, and render the population vulnerable in the health care setting (Sheppard, 2006).

Inaccessible health care information. Members of the Deaf culture have severely limited access to health information obtained through common venues such as literature, radio, and television (Pollard & Adams, 2004). An exploratory pilot study (N=5) further described that health care education is inadequate, unclear, not meaningful to culturally

Deaf adults, and providers were experienced as lacking compassion and largely ignorant to the needs of the population (Mallinson, 2004). Gilchrist's (2000) hermeneutic study found that culturally Deaf adults obtain health information primarily through their community, and that many leave the health care setting without having their questions answered or understanding the content of their visit. Steinberg et al. (2002) found that culturally Deaf women (N=45) reported negative experiences of health care, which led to avoidance of preventative health care. In a similar British study (N=27), 90% of women did not understand their provider; 50% stated that they would use preventative health care if it were appropriate for culturally Deaf adults (Ubido et al., 2002). Tamascar et al., (2000) (N=140 deaf or hard-of hearing and 76 hearing participants) showed that deaf/hard-of hearing individuals are less asked about depressive symptoms, used less health promotion programs, and had less understanding about health-related topics. In a comparison study of prelingually deaf and non-English speakers in health care, the Deaf adults were less able to communicate with the provider in their language of choice (McEwen & Anton-Culver, 1988), which further limits access to health care information.

Interpreter use. As identified in the literature, the use of an interpreter in the health care setting is controversial (MacDougall, 2000; Raifman & Vernon, 1996). A health literacy consultant describes a daughter interpreting for her culturally Deaf mother; when the client signed words that expressed depressive symptoms, her daughter spoke of "fatigue" to avoid embarrassment (Osborne, 2003). When concepts such as self-esteem become confusing to the client or difficult to translate, interpreters may unintentionally lead the conversation in a different direction (Vernon & Miller, 2001). MacDougall

(2000) proposes that an interpreter may hinder the direct therapeutic relationship between the culturally Deaf client and the provider. Raifman and Vernon (1996) submit that using an interpreter in mental health settings violates the patient's right to confidentiality. Gilchrist (2000) interviewed culturally Deaf adults and found that many clients did not want an interpreter if discussing personal matters.

Deafness as vulnerability. It may be that from a cultural perspective, Deaf adults as a whole are not vulnerable merely by nature of their hearing loss. They may be vulnerable from a social perspective (i.e., limitations by society, government, and policy) as exemplified by the struggle to prove the validity of ASL (Brueggemann, 1995) and the overall exclusion from society (Harris & Bamford, 2001). At an individual level, a culturally Deaf adult may be vulnerable by nature of genetics, social ties, human capital, social capital, or social status. The importance of social ties as defined by both Rogers (1997) and Aday (2001) helps to illustrate the benefit of membership in the Deaf culture; Bain et al. (2004) demonstrated that deaf children raised without ASL experienced loneliness and social isolation and were vulnerable to physical, social, and psychological risk associated with "being different". As 90% of deaf children are born to hearing parents (American Speech-Language-Hearing Association, 2004), these children may grow up being isolated from their parents (Leigh, Robins, & Welkowitz, 1990).

It is not the deafness that isolates and renders one vulnerable but the loss of critical social ties of family, friends, and community without a common means of communication. Depressive symptoms among culturally Deaf adults must be considered

within this context. The next section discusses the literature on depression, including what is known about depressive symptoms among culturally Deaf adults.

Depression

While there is a wealth of information available on theories and manifestations of depression, there is not a consensus in the literature on the etiology of depression. Depression theories may be labeled as endogenous (i.e., independent of situational influences), exogenous, or a combination of both (Joiner, 1999). Theories may be delineated as biological or psychosocial in nature, including psychodynamic, psychoanalytic, behavioral, cognitive, ecological, or interpersonal components (Ailey & Miller, 2004; Beevers, 2005; Taylor et al., 2000). Despite the numerous advances in pharmacology and psychiatry, scientists have not yet clearly identified the genetic or neurobiological mechanisms that may cause depression or the non-biological factors that contribute to depression or depressive symptoms (Nestler et al., 2002). The conceptual underpinnings of depression theories guide the management and treatment.

The clinical definition of depression as a syndrome includes: depressed mood and loss of interest or pleasure, associated with loss of appetite, social withdrawal, sleep disturbances, impaired concentration, and possible suicidal thoughts, is accompanied by distress or impairment, and occurs every day for two weeks or more (American Psychiatric Association, 2000; National Institute of Mental Health, 2000). From a biobehavioral perspective, the description of depression includes chronic depressive mood or emotions that interfere with daily life over time, and incorporates factors of biology, cognition, interpersonal, and life-events (Schotte et al., 2006). Guided by the

biobehavioral perspective, health care providers employ interventions which integrate biological and psychosocial aspects of treatment. The following table identifies some of the recent biobehavioral research on depression.

TABLE 2: Depression Research from a Biobehavioral Perspective

Author/Year	Purpose	Design	Sample	Findings
Agid et al. (2000)	Propose conceptual framework that addresses relationship between genetics, environmental stress, mental illness		Environmental stressors + vulnerability may either predispose one to mental illness or precipitate mental illness	
Beevers (2005)	Proposes dual process model of cognitive vulnerability to unipolar depression		Associative mode: quick effortless processing. Reflective: slow, effortful, symbolic interactions	
Campbell et al. (2003)	biopsychosocial depression, pain	Literature review	Depression has significant role in chronic pain experience. Advocate for therapies that combine medical, psychosocial modalities to pain mgmt for those experiencing both pain and depression.	
Charlton (2000)	Propose malaise theory depression		Major depressive disorder seen as inappropriate 'sickness' behavior generated by cytokine abnormalities. Propose that certain chemicals may work as analgesics on the core dysphoric emotion of malaise	
Cohen (2000)	stress and mental health	Explanatory literature review	Stress may affect mental health depending on mental state, intensity, duration, and type of physiological response, stress and relapse of depression is known; stress should be component of assessment for depression and mental health	
Higgins (2003)	Child mal-treatment and depressive vulnerability	Self-reported questionnaire, Paper-and pen measurements	N=133; 92 female and 41 male, age range 18-82 (mean 41	Levels of childhood maltreatment, childhood characteristics

			years)	(divorce, dysfunction) related to vulnerability to depression and severity of depressive symptoms as adults. Psychological factors greatest predictor.
Joiner (1999)	Examine hopelessness depression	Correlational: Attributional style, BDI, hopelessness and endogenous symptom cluster, college students		Negative attributional style more associated with hopelessness depression symptoms than endogenous depression.
Karasz (2005)	cultural aspects depression	Comparison study, interviews	36 So. Asian immigrants, 37 Euro-Americans	Non-Europeans looked for self-management and lay referral. Euro-Americans sought explanation through biology, neurology, or situational reasons
Kleinman (2004)	culture depression		Depression should be considered within the context of one's own culture. Western depression psychological, whereas other cultures may somatize.	
Kutcher et al. (2004)	Major depressive disorder pre-symptoms	Longitudinal 8 years, moms with MDD	83 healthy female adolescents (age 12-15)	Assigned to high risk group if mom had MDD (N=43) vs. low risk

				(N=40); no signif. differences in demographics, no differences in depressive symptoms or dysphoric cognitive style.
Lam et al. (2005)	Cross-cultural variations of depression	3x3 split-plot experimental design	36 American undergrad students	Provides empirical support for social construct model of illness; experience and verbal reporting of depression determined by physical, psychological, and sociological conditioning
Lewinsohn et al. (1999)	depression psychosocial risk	Prospective exploratory study	Adolescents, 286 had history MDD, 1423 did not	Dysphoric mood and dysfunctional thinking more highly correlated with history MDD, more strongly predict reoccurrence than first occurrence, major life stress greater predictor
McDermott et al. (2005)	Prevalence depression and disability	Retrospective cohort design	All individuals seen in one primary care office	Higher prevalence depression among those with history of trauma, CVA,

				mild retardation than those with lifelong disabilities (autism, CP)
Mohan and Venugopal (2000)	psychosocial theories depression		Need to differentiate normal emotions of sadness from depression. Multifactorial biopsychosocial approach best provides holistic guide to assess treat depression.	
Patel (2001)	Culture depression		Most common complaints in primary care (Western civilization) are somatic in nature, but psychological symptoms "can be elicited relatively easily on inquiry" (p. 35). Somatic symptoms historically seen as culture-developed, but now shown to be untrue. Culture may not be the significant factor in how depressive symptoms portrayed but may influence the expression/willingness to express symptoms.	
Parker (2000)	Paradigm of depression	Literature review	Dominant unitarian model focuses on severity of depression (DSM and pathways to depression), and binarian model (2 principal types) inadequate; proposes empirically based hierarchical model.	
Rapaport et al. (2002)	Exploring minor depressive	Screening for depression and functional status	226 who appeared to have minor depression	Minor depression not transitory, is characterized by mood and cognitive symptoms, may be independent of MDD or unipolar

				depression, should be seen as continuum of depression
Ryder et al. (2001)	low-grade depression	Self-report and depression instrument (BDI)	221 women, 147 men, college students age 17-33	Depressive personality disorder different from dysthymic disorder (defined by DSM IV).
Scheff (2001)	Social aspects depression	Propose concept	Endogenous theories depression propose non-situational etiologies; shame and lack of community should be considered as part of biopsychosocial components to depression	
Schotte et al. (2006)	biopsychosocial model depression	Propose model of depression, focus on vulnerability (increased risk and decreased protective factors)	Biological vulnerability = 1. Biogenic risk from genetic, gender, temperament and 2. Psychological risk from trauma, maladaptation, gender, poor coping, intergenerational. Psychological vulnerability = 1. Somatic risks from somatic disease, gender, substance abuse and 2. Social-cultural risk from instability, insecurity, gender, environmental factors. Gender depends on which factor of vulnerability discussing. Protective factors: material prosperity, good health, decreasing stress, loving family, supportive social network, social solidarity, social skills, meaningful activities. Depression as development of negative spiral.	
Street et al. (2001)	Propose framework depression	Quantitative integration depression	99 factors identified from 27	4 Dimensions: 1. cognitions → lack of

		factors	theories (14 original theorists)	interpersonal and intrapersonal communication. 2. Behaviors and impact of environmental stress 3. Pursuit of unrealistic goals and perceived lack of control 4. Self-focus and self-reinforcement
Trask (2004)	Assessing depression in cancer patients	Literature review	Many factors may affect appearance of depression such as timing of assessment, age, gender, race/ethnicity, hospitalization status, type and stage of cancer; need to develop instrument specific for this population that considers each of the above factors.	
Wals & Verhulst (2005)	antecedents to depression child	Literature review	Childhood mood problems strongly associated with mood disorder later, childhood environmental risks associated with adult depression	

Vulnerability connotes a weakness or condition, whereas risk indicates the potential for damage. One can be vulnerable to symptoms of depression by virtue of gender and genetics. In fact, genetics have been proposed as a significant factor in the development of major depressive disorder (Goodyer, Tamplin, Herbert, & Altham, 2000). Gender plays a part in depression, as female are twice as likely to develop depression as males (Abela, Aydin, & Auerbach, 2006). Many factors increase one's risk for depression, such as stress, traumatic life events, chronic illness, pain, poor coping

mechanisms, and social isolation. The next section discusses the role of stress in depression.

Stress and Depression

Stress is increasingly recognized as precipitating depressive symptoms or exacerbating the symptoms of depression. Mental and physical stress has been shown to increase one's risk of depression (Abela, Aydin, & Auerbach, 2006; Agid, Kohn, & Lerer, 2000). Stress is a uniquely individual experience, and researchers such as Cassidy (2000) and those at the Basic Behavioral Science Task Force of the National Advisory Mental Health Council (1996) have questioned why some individuals experience depression in the presence of biological disease or physical stress while other individuals appear to have self-protective resilient qualities that decrease the risk of depression. Scheff (2001) views depression as a response to stressful components of one's immediate social influences in the face of endogenous (i.e., biological and genetic) factors.

Biological Perspectives of Depression

Depression has been examined genetically, and some biobehavioral researchers have sought a relationship between genetics and stress-precipitated depression. A neurokinin 1 receptor and its antagonist SLV-323 has been studied in animals as to its possible role in psychosocial stress and depression and were found to be significant (Czéh et al., 2005). Goldberg (2006) investigated the genetic predisposition toward depression and gender differences, and concluded that environmental factors may modify the genetic influence. Taylor et al. (2000) suggests that gender studies of depression should explore the difference between the female "tend and befriend"/attachment-

caregiving and oxytocin levels and the male "fight or flight" response to stress. Despite the vast research on the etiology of depression, Nestler et al. (2002) and Schotte et al. (2006) describe the state of the science as disappointing, as it lacks definitive causality.

The literature illustrates the expanding knowledge of depression among those experiencing pain or illness. Emotional distress and fatigue have been shown to precipitate depression in patients with coronary heart disease (Denollet & De Vries, 2006). Physical pain that stems from disease or illness may also have profound psychosocial effects that can lead to depression (Campbell, Clauw, & Keefe, 2003). Jenerette, Funk, and Murdaugh (2005) have explored depression among those with sickle cell disease, and found that depression may be related to the stigmatizing effects of the disease. Depression has been described biobehaviorally among those with cancer (Trask, 2004), those with medical co-morbidities (Simon & Von Korff, 2005), and among individuals with multiple sclerosis (Patten, Lavorato, & Metz, 2005).

Developmental life stages may influence the phenomenon of depression. Social and psychological trauma and biological alterations of corticotropin-releasing factors of childhood were found to predispose one to adult-onset depression (Wals & Verhulst, 2005). Gallo et al. (2003) have explored cognitive and functional changes in elderly individuals and found that memory and problem-solving abilities were significant mediators to the experience of depression. Murray et al. (2006) demonstrated that many older people and their health care providers accept depression as a natural course of biological aging and social isolation.

Biobehavioral Perspectives of Depression

A biobehavioral understanding of depression proposes the interrelationship between the physiological, behavioral, sociological, and psychological elements (Mohan & Venugopal, 2000), and seems to best complement the holistic health care model of advanced practice nursing. Biobehavioral perspectives of depression are driving the development of new treatment modalities, and may lead to chemical interventions such as Selective Serotonin Reuptake Inhibitors (SSRI) or MAO-inhibitors. Cognitive or behavioral models of depression are frequently associated with cognitive-behavioral treatment. Guided by the biobehavioral model of depression, interventions may include a combination of therapeutic modalities (De Raedt, 2006). When the etiology of depression is explored with the client from the holistic perspective of genetics, biological, psychological, and sociological influences, the provider and client can develop appropriate and meaningful interventions.

Cultural influences of depression and depressive symptoms have been explored and described (Karasz, 2005; Kleinman, 2004; Patel, 2001). Cultural determinants of depression may include factors of biology, genetics, economics, gender, and social variations; culture may also influence the manifestations of depression. One's culture may affect the somatic and psychological manifestation of depression (Patel, 2001). Medical and neurobiological comorbidities may exacerbate depression, and race and gender are seen as further complications to the phenomenon and the experience (Kales & Mellow, 2006). Certain ethnic groups may view depression as a social or emotional reaction, and

researchers (Karasz, 2005; Kleinman, 2004) are recognizing the need for culturally sensitive research on depression and interventions.

The literature contains biobehavioral theories and conceptual models that have stemmed from research on cognitive aspects of depression. Diathesis-stress models of depression propose that the diathesis (i.e., a physical, mental, or emotional condition) is triggered in times of stress and may precipitate depressive symptoms or depression (Coyne & Thompson, 2003).

Agid et al. (2000) hypothesized a relationship between stress and genetics; they contend that genetic predisposition may influence the risk of illness as well as vulnerability to stress-induced depression. Their conceptual framework addresses an individual's likelihood of being exposed to repeated stressors, based in part upon experiencing early parental loss, and how significant life events lead to depression. It is the relationship between genetic susceptibility and environmental stress that is the precursor to depression.

The diathesis-stress theory of depression (Coyne, 1976) proposed that depression is maintained and even exacerbated by specific interpersonal interactions; depressive symptoms may be initiated by a significant loss of self-esteem, then when reaching out and subsequently rejected by others, the individual begins a gradual downward spiral.

Abele et al. (2006) examined the diathesis-stress component of depression and hypothesized that individuals with greater depressogenic inferential style (i.e., the perception that negative events will always happen because of the person's way of being) experience stressors as more significant, which leads to increased depression. Participants

were given a baseline assessment for depression and depressogenic inferential style, with eight follow-up assessments every six weeks. Findings confirmed that those who experience stress on a very personal level experienced more depression than those who were able to view the stress as a separate and impersonalized event.

An emerging biobehavioral conceptualization of depression stems from the theories of depression and development. Berry (2004), a nurse researcher is directing her inquiry to the relationship between depression and emerging adulthood, focusing on individuals age 18 to 25. Berry hypothesizes that the transitional period from late adulthood to adolescence is a separate and distinct phase of life, and the expression of depression is influenced by the associated developmental factors. Although depression in childhood affects males and females equally, by mid-adolescence, females are at significantly greater risk for depression; Berry hypothesizes that this gender difference is being influenced by the transitional period (2004). She concludes that although references such as the DSM (American Psychiatric Association, 2000) propose the same depression criteria for children, adolescents, and adults, biobehavioral research on depression must address each developmental stage of life uniquely.

The hopelessness theory of depression originally proposed by Abramson, Metalsky, and Alloy (1989) has been further investigated from a biobehavioral perspective. Joiner (1999) hypothesized that hopelessness plus endogenous factors affected the phenomenon of depression. Participants were examined for symptoms of endogenous depression (i.e., depressive symptoms independent of psychosocial factors), and compared with individuals experiencing negative attributions and hopelessness (e.g.,

exogenous factors). The author concluded that although hopelessness overlaps endogenous factors of biology and genetics, hopelessness is more significant in the development of depression.

Cytokines have been identified as having a significant role in the symptom experience of disease, and their role is being explored in depression. The malaise theory of depression (Charlton, 2000) hypothesizes that abnormalities in cytokine levels creates a 'sickness behavior'. The effect of the sickness behavior causes dysphoric emotions (e.g., malaise). The combination of the sick role coupled with alterations in cytokines predisposes the individual to depression. The author further hypothesizes that antidepressants provide depression symptom relief by exerting an analgesic action on the dysphoric emotions.

Schotte et al., (2006) conceptual model of depression offers a holistic and biobehavioral understanding. The model proposes four quadrants (e.g., biological, cognitive, emotional, and historic) that intersect to increase one's vulnerability to and risk of depressive symptoms; available resources are protective factors that may reduce the risk of depression (Schotte et al., 2006). Key concepts include risk, resources and protective factors, and prolonged exposure to stress. Schotte et al. (2006) propose that emotions and self-image are governed by biological and genetic processes, and biological functioning is equally influenced by experiences, feelings, and beliefs. The model is another conceptualization based in part on the diathesis-stress model of depression. Genetics, biology, and socio-psychology interact when exposed to stress, and can provoke symptoms of depression. Treatments have been guided by the conceptual model,

with health care providers directing patient education and health care interventions at normalizing symptoms, reducing symptoms, encouraging mindfulness and play, and rehabilitation. The intervention goal is to shorten the duration of depressive episodes and to prevent recurrence.

Application of Theories/Conceptual Models to Culturally Deaf Adults

In the absence of any mediating or moderating influences, behavioral theories of depression may have limited applicability in research, identification, or treatment of depression in certain populations (Ailey & Miller, 2004). While many of the following theories or models of depression could readily be applied to culturally Deaf adults, their methods of assessment may be limited for the population. Asking clients to report on their behavior or emotion may pose cognitive challenges (Schwarz & Oyserman, 2001); given the language barriers, self-reporting could lead to misunderstanding and misinterpretation. In Beck's cognitive theory, individuals with dysfunctional attitudes are more likely to experience automatic thoughts consisting of negative perceptions of self while experiencing depression (Tanaka et al., 2006). While such automatic thoughts undoubtedly occur among culturally Deaf adults, concepts such as perceptions of self could be difficult for culturally Deaf adults to describe or relate to a health care provider not familiar with the culture. Dual process models (e.g., interaction between automatic and controlled thoughts) of cognitive vulnerability propose that people possess two modes of information processing, one that necessitates quick processing of well-learned associations and another that employs slower processing of symbolic inferences (Beevers, 2005); culturally Deaf adults may express their associations and symbolic

inferences from their unique cultural knowing in ways that could create misunderstanding and misdiagnosis. Depression is often managed by breaking down symptoms and using cognitive, behavioral, or cognitive-behavioral therapy (Coyne & Thompson, 2003; Starr & Moulds, 2006).

Psychosocial theories of depression are vast and diverse. In fact some researchers propose that psychosocial theories of depression are too diverse, and contend that there is little understanding of the original theorists' conceptualization of the key themes underlying psychosocial theories of depression (Street, Sheeran, & Orbell, 2001). Ailey and Miller (2004) advocate that applying psychosocial theories of depression to marginalized people such as culturally Deaf adults continues to reflect their marginalization and oppression. One proposition that may provide an important perspective of depressive symptoms among culturally Deaf adults is the belief that lower perception of justice (i.e., from those in a position of power over the individual) should be viewed as a predictor of poorer health and is associated with increased risk to health (Elovainio et al., 2002); the literature identifies lower perception of justice and marginalization among disabled people such as culturally Deaf adults.

There may be a relationship between the number of stressful events experienced and the degree of perceived stress, and confidence may be an outcome of coping with daily stresses (Cassidy, 2000). As demonstrated in Cassidy's (2000) study, those reporting more frequent illness felt more helpless in problem situations and experienced more external locus of control. While interpersonal theories of depression have been limited in application among vulnerable populations, they may hold potential for use

among vulnerable populations (Ailey & Miller, 2004). One hopelessness theory proposes that an individual is as vulnerable to depression as his or her most depressogenic inferential style, and depressive affect is triggered by stressors; depressogenic individuals attribute the cause of negative events to constant factors, and infer that negative events indicate future negative consequences and negative perception of self (Abela, Aydin, & Auerbach, 2006). Family dysfunction in childhood has been shown to be a significant predictor of depression, vulnerability to, and risk of depression (Higgins, 2003), and as 90% of deaf children are born to hearing parents, discussing the level of childhood family support would be an important component of the dialogue between the culturally Deaf adult and primary care provider.

The literature illustrates that members of ethnic and racial minorities are less likely to discuss depressive symptoms or seek care for depression. One hypothesis is that members of minority populations may feel that depressive symptoms are social problems or emotional reactions to situations (Karasz, 2005). Loneliness and social isolation may be experienced by culturally Deaf adults, however depression and anxiety among Deaf adults are more likely related to the accommodations of deafness rather than the experience of deafness (Knutson & Lansing, 1990). Depression may be experienced or expressed in a variety of ways among people of differing cultures. The Cultural Construction of Illness Model (CCIM) explains that certain components of depression such as sadness and worthlessness are described in Western cultures more frequently than in Eastern cultures (Lam, Marra, & Salzinger, 2005). Culture is noted to play a part in the under-diagnosis or misinterpretation of symptoms (Kleinman, 2004), and this certainly

needs to be addressed in theories of depression among culturally Deaf adults. There may be a direct relationship between severity of depression and lower education (Myers et al., 2002), and as culturally Deaf adults have generally lower educational levels than hearing persons (Pollard & Adams, 2004), educational level may have an impact on depressive symptoms.

State of the Science: Depression and Culturally Deaf Adults

The etiology and treatment of depression among deaf/Deaf persons may be assessed and treated from a medical or cultural perspective. The provider guided by the medical model may assume that depression or other mental health problems are a result or consequence of deafness (Carvill, 2001; Roberts & Hindley, 1999). Some theorize that congenital or prelingual hearing loss can effect social, intellectual, and emotional development, leading to personality traits such as egocentricity, difficulty in empathizing with others, rigidity, and impulsivity (Martin & Clark, 2000). The cultural model does not presume a link between deafness and depression; however, a culturally competent provider may consider the cultural influence on the manifestations of depression, how it is expressed or described, and how a diagnostic label and intervention might be affected by culture.

A literature search showed no nursing studies that examined depression and deafness. Depression among deaf, hard-of-hearing, and culturally Deaf adults has been researched among disciplines such as medicine, psychology, and sociology. Researchers examining depression among culturally Deaf adults propose that biology, ethnicity,

religion, education, occupation, and social experience are all determinants of mental health for culturally Deaf adults (Leigh & Pollard, 2003).

The relationship of congenital deafness to depression has been explored. Researchers such as Carvill (2001) and Carvill and Marston (2002) propose an increase in mental health issues such as depression among congenitally deaf individuals, and a similar link has been described (Martin & Clark, 2000) in a textbook of audiology. Leigh and Pollard (2003) and Pollard (1998) argue that it is not the congenital deafness that predisposes one to depression but the biobehavioral life events and circumstances that lead to depression.

Stress Factor

The diathesis-stress models of depression as discussed previously are applicable to culturally Deaf adults. E. Jones, Ouellette, and King (2006b) have shown in an intervention study (N=105) that culturally Deaf adults may have higher levels of perceived stress. Roberts and Hindley (1999) demonstrated that culturally Deaf adults experience stress in the health care setting, which is exacerbated by communication barriers. Difficulty interacting with the hearing world is associated with depression, social introversion, loneliness, and social anxiety, and relates more to accommodations of deafness (Knutson & Lansing, 1990). Although proponents of the cultural model of deafness contend that deafness is a characteristic rather than a diathesis, navigating through a hearing world could be the diathesis and an event such as needing health care could be the stressor that increases one's risk of depressive symptoms.

There is nothing in the literature to suggest that deafness per se causes depression. However, difficulty interacting with the hearing world is associated with depression, social introversion, loneliness, and social anxiety, but relates more to accommodations of deafness (Knutson & Lansing, 1990). The General Health Questionnaire was back-translated and administered to 102 British Sign Language signers (Ridgeway, 1997); the conclusion was that people with negative attitudes toward their deafness and toward hearing people are more likely to suffer from depression and anxiety (as more study participants were postlingually deaf, this conclusion may not be generalizable to culturally or prelingually Deaf adults).

Communication and Cultural Factors

Studies have compared depression between deaf English-speakers, culturally Deaf adults, and hearing adults, with varying results. De Graaf and Bijl (2002) conducted interviews (N=523) with hearing and prelingually deaf participants and found that those with more communication problems and lower self-esteem had more mental distress; 22% of hearing men, 27% of pre and postlingually deaf men, 26% of hearing women, 32% of prelingually deaf women, and 43% of postlingually deaf women had mental distress (the study was conducted in a different language than ASL, and most prelingual participants used speech-reading so results may not be comparable to culturally Deaf adults in the U.S.). Watt and Davis (1991) found that deaf students showed more boredom and depression than hearing students; the study was conducted using the Beck Depression Index, which may not have conceptual, functional, or semantic equivalence. Leigh, Robins, Welkowitz, and Bond (1989) examined prelingually deaf and hearing

college students; while prelingually deaf participants demonstrated more signs of mild depression, the sample was drawn from a population of college students and English speakers and may not reflect the culturally Deaf population. In a similar study, Leigh et al. (1990) found that deaf students who use spoken English had better communication with their mothers and had less depression than those who use ASL and whose mothers do not sign. Leigh and Anthony's (1999) study examined adults using mental health services and showed that prelingually deaf (N=12) appeared to have less depressive symptoms than hard-of-hearing individuals; the results were not significant, and it is unclear if the prelingually deaf adults used ASL.

Researchers have explored the relationship between depression and the age of hearing loss. Using focus groups, Luey, Glass, and Elliott (1995) noted more depression among those with hearing loss acquired later in life. In a study of prelingually and culturally Deaf adults age 65 and older (N=45), depression and insomnia were noted (Werngren-Elgstrom et al., 2003). Elderly culturally Deaf adults may have more dependence with activities of daily living due to communication barriers, but also had better perceptions of health (Werngren-Elgstrom et al., 2005) than elderly hearing people. Studies have compared depressive symptoms between deaf, blind, and unimpaired individuals. One study showed that hearing impaired college students in Japan may have more mental health challenges than blind students (Yoshida, Ichikawa, Ishikawa, & Hori, 1998), however, the differences in educational systems and support services between the U.S. and Japan make it difficult to generalize to prelingually or culturally Deaf adults in the U.S. A nursing study by Koenes and Karshmer (2000) compared depression among

deaf and blind college students, and found that depressive symptoms were more prevalent among blind students, as accommodations to visual impairments were more stressful and difficult than accommodations to hearing loss.

Assessment of Depression among Culturally Deaf Adults

Communication may play a significant part in the manifestation of depressive symptoms among culturally Deaf adults. Linguistic competence significantly impacts the range of symptoms elicited during interviews (Roberts & Hindley, 1999). Deaf children have a higher risk of mental health problems, which may be more related to communication, enculturation, or isolation (Tong, Cornes, & Wiltshire, 1999). Steinberg et al. (1998b) have ascertained through interviews with culturally Deaf adults (N=54) that the concept of depression is vaguely understood in ASL but not in written English.

Depression screening instruments for culturally Deaf adults have been tested, and most researchers concur that these instruments are inadequate for the population. Cornes and Wiltshire (1999) conducted a literature review on instrumentation and mental health among culturally Deaf adults and identified the need for translation of psychometrically sound depression assessment tools. Leigh and Anthony-Tolbert (2001) examined the Beck Depression Index-II for reliability using zero-order, part correlations, with test-retest score of .74; however, the sample was drawn from deaf college students (reading level may be higher than among most culturally Deaf adults with 5th grade reading level), and participants were not necessarily fluent in ASL. Researchers compared the Zung Self-Rated Depression Scale in written English with an ASL version (N=71, 30% of participants had college degrees and 20% of participants had 10th grade reading

levels); the ASL versions showed better applicability for those with lower literacy, but was shown to be less sensitive for screening depression (P. Zazove et al., 2005).

The literature illustrates numerous difficulties in assessing depression among culturally Deaf adults. Concerns include cultural insensitivity, communication difficulties, inappropriate or incorrect use of interpreters, and culturally prescribed behaviors that may mask or confound the appearance of depression (Leigh & Pollard, 2003); these are not adequately addressed in the classic textbooks, despite the evidence that a separate discussion is needed (Lala, 1998). As demonstrated in case studies (N=12 deaf or blind participants) (Carvill & Marston, 2002) it is difficult to assess depression without validated instruments. Chart reviews have shown erroneous reports of causality in mental health concerns among culturally Deaf adults, overlooked or misdiagnosed signs/symptoms among the population (Pollard, 1998).

Misdiagnosis of mental health problems often stem from miscommunication. For example, a chart review of deaf inpatients concluded that noted disparities in mental health care are due to barriers in communication, misinterpretations of fundamental concepts, and errors in interpreter use, which led to erroneous labels of psychosis (Briffa, 1999). In a comparison study of 28 prelingually deaf patients hospitalized for mental health problems, Shapira, DelBello, Goldsmith, Rosenberger, and Keck (1999) noted that 70% were misdiagnosed, while only 56% of hearing people were misdiagnosed. A culturally Deaf adult discussed her experience seeking care for depression; she felt stigmatized, frustrated, felt that treatment was superficial, and discussions with health care providers were minimal (DeVinney & Murphy, 2002).

Studies have explored attitudes of hearing health care providers toward culturally Deaf adult patients in the mental health setting. In a survey of deaf adults and hearing providers in Britain, Cooper et al. (2003) found that older mental health providers felt more comfort toward deaf clients than younger providers, and those who felt comfortable with homosexual clients also felt more comfortable with deaf clients. In a U.S. survey (N=73), only 22% of respondents use an interpreter in health care; 63% used written English to communicate, despite awareness of poor literacy rates (Ebert & Heckerling, 1995). In semi-structured interviews with 14 culturally Deaf adults, Iezzoni et al. (2004) had similar findings: providers rely on written communication, while participants preferred ASL. In Gilchrist's (2000) hermeneutic study, Deaf participants described their experiences with nurses who rolled their eyes or made faces when providing care. Hauser, Maxwell-McCaw, Leigh, and Gutman (2000) described culturally insensitive interactions from mental health providers, who often focused on the nature of deafness rather than the client's concerns. Similar findings were noted in a physician survey (N=480): providers often focused on different themes than what was important to the culturally Deaf client (Leigh, Vash, Powers, & Nettles, 2004). A physician survey (N=165) found that providers felt distrust from their culturally Deaf clients and experienced these clients as more time-consuming (Ralston, Zazove, & Gorenflo, 1996). Culturally Deaf adults may be diagnosed with certain conditions more than hearing adults in such a way as to suggest clinician bias (Harmer, 1999), although the author does not offer citations or examples to substantiate this statement. A review of case studies

showed that 40,000 culturally Deaf adults have serious mental health problems, and only two percent receive the needed care (Pollard, 1996).

At Risk for Depression

The biobehavioral phenomenon of depression as conceptualized by Schotte et al. (2006) addresses risk, resources, and protective factors. Vulnerability is described as a psychobiological substrate that increases the risk of depression. Early childhood trauma renders one biologically and psychologically vulnerable to depression. Younger people are also identified as more vulnerable when stressful factors are considered within the context of their society (Schotte et al., 2006). Sullivan and Knutson (1998) found that 6.1% of neglected or abused children in the United States are deaf; associated with increased risk of abuse is an increased risk of Post-Traumatic Stress Disorder and subsequent depression. Furthermore, culturally Deaf adults with co-morbid disability are at increased risk of physical and sexual abuse (MacDougall, 2000), and 30% of congenitally deaf children have co-morbid disability (American Speech-Language-Hearing Association, 2004).

Sociocultural factors increase vulnerability to depression (Schotte et al., 2006). Tong et al. (1999) demonstrated that deaf children are at increased risk of mental health problems, and this risk can be mitigated in part by acceptance within the Deaf culture. As 90% of deaf children are born to hearing parents (American Speech-Language-Hearing Association, 2004), these children may grow up being isolated from their parents (Leigh et al., 1990). Bain et al. (2004) illustrates the risk of depression for deaf English-speaking speech-reading adults; these individuals experienced loneliness, isolation, and the self-

perception of being 'different'. Risk for culturally Deaf adults has been described in the health care setting as receiving less than optimal care (Barnett, 2002; Connolly et al., 2006; Gilchrist, 2000), being stereotyped (Leigh & Pollard, 2003), and leaving the health care setting without having one's concerns addressed (Gilchrist, 2000; Mallinson, 2004).

Stress is a critical aspect of vulnerability to depression. A prolonged state of biological stress causes hyper-arousal and major changes within the central nervous system; therefore, the normal coping mechanisms for reducing stress may no longer be effective (i.e., labeled a depressogenic process). Emotional distress sets off a negative or downward spiral; the process is compounded by cognitive factors, biological processes, depressive symptoms, and interpersonal factors (Schotte et al., 2006). For culturally Deaf adults, increased risk may be experienced as stress.

Having resources may minimize or ameliorate one's vulnerability to depression. For culturally Deaf adults, these resources usually stem from the social support and social ties within the culture. Rather than repeated exposure to diagnostic tests and interventions to cure deafness, the Deaf culture may protect its members and validate the members as 'normal' (de Halleux, 2001). The cultural view of deafness reduces stigmatization for its members, and provides resources that transform deafness from a depressing disability to a cultural richness (M. Jones, 2002). S. Rogers et al. (2003) examined the Deaf culture for signs of resilience and found that interpersonal, behavioral, and environmental assets within the individual and the culture are protective factors that reduce the risk of depression.

Summary

It is quite plausible that one or more of the extant theories of depression can be used to guide assessment and intervention of depressive symptoms among culturally Deaf adults. However, given the lack of literature available that describes depressive symptoms among the population, we cannot dependably meet the primary health care needs for culturally Deaf adults. Holistic primary health care necessitates understanding how culturally Deaf adults describe depressive symptoms and how culturally Deaf adults experience depressive symptoms. Providers must address the linguistic and cultural challenges faced by culturally Deaf adults, recognize that words and phrases cannot be literally to or from translated from English to ASL, and that written communication between primary care provider is unreliable and unrealistic. A culture-specific tool must be developed that enables primary care providers to screen culturally Deaf adults for depressive symptoms. Only when these steps have been taken can we begin to reduce the significant health care disparities among culturally Deaf adults.

A biobehavioral understanding of depression and depressive symptoms complements holistic advanced practice nursing and research. This study describes depressive symptoms from the perspective of culturally Deaf adult individuals, as expressed in their native language (ASL); such knowledge will help primary care providers to discuss depressive symptoms with their culturally Deaf clients in words that are meaningful and culturally relevant to the population. Chapter two reviewed the literature describing the unique culture of the Deaf. The concepts of vulnerability and depression were described and explored with regard to the culture of the Deaf.

CHAPTER III: METHOD

Chapter III defines the method for the proposed study. Content includes a description of the study method, the role of the interpreter, procedures for human subject protection, the sampling procedure including recruitment, the process of data collection, data analysis, and the method of ensuring rigor.

Study Method

The study purpose was to explore depressive symptoms among culturally Deaf adults, in order to describe the experience, the words, and the shared meaning of the experience. It is through language that understanding becomes possible. The exploratory study employed a hermeneutic phenomenological methodology. Fleming, Gaidys, and Robb's (2003) hermeneutic outline and Gadamer's philosophy provided a guide to the study design, which facilitated a description of depressive symptoms in the words and meaning that express the perspective of a sample of culturally Deaf adults.

Hermeneutic interpretive phenomenology includes the concepts of tradition, the hermeneutic circle, and fusion of horizons. In general, tradition is based on a shared culture, history, and language passed down through generations, which forms the present and helps to shape the future. Knowledge does not reside within an individual but within tradition; ontologically, we come into being through tradition (Gadamer, 1975). In hermeneutics, tradition is dynamic and is shared (Geanellos, 1998). The researcher attempts to enter the hermeneutic circle of understanding (i.e., a metaphorical representation of the art of understanding). Fusion of horizons is an awareness that each person has limits to their own unique perspectives, and that to come to mutual

understanding, these perspectives must intersect and form a new way of understanding (Annels, 1996).

The researcher is the instrument in hermeneutic studies (Annels, 1996; Geanellos, 1998; Knoblauch, 2005; Munhall, 2001). Research questions usually begin with broad concepts, and are often expressed in open-ended phrases. Research strategies include engagement with people in naturalistic settings, and necessitate high involvement on the part of the researcher. Methods of collection include observation, and semi-structured or unstructured interviews. Analysis is enhanced by self-reflection and journaling. The findings are reported as a narrative, which provides descriptions of people living through events and experiences. Sampling is non-probability and purposive; the researcher seeks participants who can best speak to the phenomenon or experience in order to obtain the richest information. Sampling continues until saturation is attained (no new information is forthcoming from participants).

Steps used in this study included: deciding on a question, identifying pre-understandings, gaining understanding through dialogue with participants, gaining further understanding through text, and establishing trustworthiness. Data were collected through hermeneutic interviews and observation, in a location mutually selected. The researcher conducted all interviews using American Sign Language (ASL), and was aided by two certified interpreters (although the researcher is bilingual in ASL/English, she is not a professional interpreter; two interpreters were used throughout the study to enhance consistency of dialogue).

Interpreters

The certified interpreters were a vital part of the study. The interpreters were identified to the participants prior to conducting the first interview and each participant was told that they could withdraw from the study if they did not wish to work with the selected interpreter. The expectation was to use the same interpreter for all interviews, however, several participants requested to bring their "own" interpreter to the interviews. Ultimately, two certified interpreters were used during the interviews. Each interpreter was required to pass the Human Subjects Protection test, as required by the University of Arizona prior to participating in the study. Criteria for selecting the interpreter included ASL-English certification, 5 or more years of experience as a certified interpreter, availability for interviews during times and dates of data collection, and willingness to complete human subjects training (training was available online) for University of Arizona.

Dr. Elaine Jones provided guidance and oversight with the training for the interpreters. Training included review of human subjects protection and research ethics, the interpreter's role in research (which differed from traditional interpreting), discussion of the training videotape regarding conceptual accuracy (e.g., using back-translation exercise), and practicing in-person interviewing and interpreting with a volunteer Deaf adult. Training also included a review of logistics of concurrent videotaping and audiotaping of the interpreter's voiced translations (e.g., ALS to spoken English), and attention to lighting and camera angles. Each interpreter spent approximately five hours with the human subjects training modules. Further training, discussion, practice sessions,

translation and back-translation exercises, and practice with camera and lighting took an additional eight hours per interpreter.

Procedures for the Protection of Human Subjects

The research study met the definition of clinical research. The Human Subjects framework and consent form followed the guidelines for the University of Arizona. Institutional Review Board (IRB) approval was obtained from the University of Arizona prior to recruitment of volunteer participants.

Human Subjects Protection

The questions asked during all interviews were limited to the participant's experience of sadness and depressive symptoms. Participants were reminded prior to each interview that they could refrain from answering any questions that felt uncomfortable, the interview could be stopped at any time, and the participant could withdraw from the study at any time without repercussion. The participants were advised prior to consent and before each interview that the interviews were to be video-recorded.

Participants were informed that some questions might feel stressful or upsetting, but that questions would be limited to the experience of sadness and depression. Prior to each interview, participants were reminded that they did not have to answer any questions that felt uncomfortable and they could stop the interview at any time. Although the researcher is an Advance Practice Nurse, her role in this study was purely that of researcher. She reiterated that although she is a nurse, her role was not to diagnose or offer any medical advice or counseling. She identified to all participants that she would

refer any participant to the primary health care provider or to Nevada Mental Health Center if the participant desired; contact information was made available.

The participants will not be personally identified in any reports or publications that may result from this study. Only the researcher and her dissertation committee have access to the information provided by the participants. The notes taken during the interviews, the recordings, and the written narrative identified all participants by pseudonyms, and all data sources were stored in a locked cabinet at the researcher's place of employment (i.e., University of Nevada, Reno). The video discs were destroyed by shredder after analysis was complete; the narrative (i.e., text) will be kept in the same locked cabinet at University of Nevada, Reno, for 3 years and then destroyed by shredder.

Consent

There may be varied levels of understanding among culturally Deaf adults, which is especially important when seeking volunteer participation and obtaining written consent. Dr. Jones supervised the translation of the University of Arizona Human Subject Protection-approved written English consent form (i.e., consent for videotaping interview) into ASL. The ASL-signed consent was recorded onto DVD for easy presentation on a laptop to individual participants. The second participant interviewed appeared not to understand some components of the ASL-signed consent. A second DVD was thus made, using simpler ASL signs, and the participant was re-consented. Participants were given a copy of both the written English consent form and the ASL/DVD-generated consent form.

The researcher obtained ASL-signed consent of the participants, with the certified interpreter present to assist with questions or concerns. Written consent was then obtained as follows:

- ◆ All participants were urged to ask questions of the researcher prior to signing consent form;
- ◆ Signed written consent was obtained before conducting any interviews;
- ◆ Written consent was obtained in private, with only the researcher, participant, and interpreter present.

Consent forms are being stored in the Office of Nursing Research, College of Nursing, at University of Arizona.

Sample

Nine culturally Deaf adults participated in this study. The male and female participants were age 21 and older, and included some minority representation. In hermeneutic research, the number of informants is not as important as the descriptions and level of saturation that is obtained during interviews (Crist & Tanner, 2003). Good informants are those who not only have or are experiencing the phenomenon under investigation but are also willing to talk about it (Annels, 1996; Crist & Tanner, 2003; Fleming et al., 2003).

Recruitment of Participants

Of the 300,000 residents within the geographical area of Northern California and Nevada, it is estimated that 45,000 are hard-of-hearing. Based on the prevalence of depression and prelingual deafness, it was anticipated that many were pre-lingually deaf

and may have experienced depressive symptoms. Participants were sought from the area of Northern Nevada and Northern California. Although the geographical region is quite large, the city of Reno serves as the primary source for health care for many individuals, and is the secondary source of referral care for most residents in the area. There are no primary health care providers who 'specialize' in care to the culturally Deaf adult. One health care center in the city of Reno has an APN on staff that is considered fluent in ASL. There are no statistics available that describe the prevalence of culturally Deaf adults within the geographic region.

Recruitment was done through solicitation of volunteers; flyers were posted at various health care centers, hospitals, and Deaf community event centers within the geographic area. Potential participants were asked to contact the researcher by TTY (i.e., equivalent to telephone) or e-mail. The flyer was written in terms that were understandable to culturally Deaf adults (e.g., 5th grade reading comprehension). The purpose and study process was identified. Common depressive symptoms were listed in terms understandable to the population; to help distinguish between normal sadness and depressive symptoms, individuals were asked to volunteer if they had experienced three or more simultaneous symptoms that have disrupted daily life (e.g., such as change in sleep, eating, or loss of interest).

Identifying a targeted enrollment is inconsistent with phenomenology, in which anyone who can speak to the phenomenon is invited to participate; however, effort was made to recruit 50% women and minority representation as per area demographics. Fliers

were also placed in health care centers that are frequented by people of non-white race and ethnicity.

Many culturally Deaf adults feel distrust toward the hearing population and the medical community (Meador & Zazove, 2005). The researcher therefore heeded the advice presented in the literature to contact a member of the culturally Deaf adult community that is well respected and is familiar with research, to serve as a culture broker. The culture broker's role was to mediate between the researcher and members of the culturally Deaf community for the purpose of producing change or reducing stress and conflict (Jezewski, 1993). The researcher had formed a collaborative relationship with a culturally Deaf woman who is completing her doctoral studies in social psychology. This culture broker introduced the researcher to the culturally Deaf adult community by accompanying the researcher to community functions and events, which allowed members of the population to get acquainted with the researcher and gain comfort with her presence. The culture broker assisted with recruitment and screening to help ensure that potential participants understood the purpose of the study, the process (i.e, three interviews), the time commitment, and the lack of compensation. The culture broker did not participate in data collection or analysis, as the concept of confidentiality can be perceived as "keeping secrets" (Meador & Zazove, 2005); this might have placed the culture broker or participants in an uncomfortable position.

Data Collection

Data were collected through interviews and observations. A significant aspect of hermeneutic data collection includes journaling and reflection. Reflection is a critical part of the hermeneutic process, and occurs throughout data collection and analysis.

Interviews and Observations

The interviews took place at a location mutually chosen by the participant and researcher that allowed for private communication. The interviews were videotaped in order to capture the facial expression and body language of the participant; this became important during review and analysis, as facial expressions are used by Deaf adults to emphasize a point, to qualify and quantify statements, and to enhance the ASL signs. The videotapes also recorded the voices of the interpreter and researcher. Interview steps included:

- 1) Researcher presented questions in voiced English
- 2) Interpreter translated from voiced English to ASL
- 3) Participant responded in ASL
- 4) Interpreter translated from signed ASL to voiced English

The videotape of every first interview was reviewed by the interpreter and the researcher. Random portions of the videotapes with ASL and voiced translations were viewed with a second interpreter for consensus on the conceptual accuracy of English-to-ASL and ASL-to-English interpretation; at least one interview with each participant was reviewed by the second interpreter with the researcher's participation. The primary interpreter and the researcher initially had some difficulty understanding two participants,

and all of the videotaped interviews with these participants were reviewed by the researcher and both interpreters. After one participant requested a different interpreter (the second interpreter hired for this study), it was evident that her vocalizations were easier for the researcher to understand and transcribe. She became the primary interpreter for the duration of the study. After being reviewed for accuracy of transcriptions and data quality by a second ASL interpreter and two dissertation committee members, the DVD recordings were transcribed and then destroyed.

Each initial interview began with an open-ended question, "I would like to learn about you – can you tell me about yourself?" Further questions were used to help distinguish between feelings of normal grief or sadness, and mood changes that disrupted daily life. Other questions included "why are you sad", "have you been sad 1 week?" "Sad 2 weeks?" "Do you remember not feeling sad?" "How does your body feel when you are sad?" The concept of depression may not be translatable. The researcher followed the culture broker's suggestion to use the word 'sad' in lieu of the word 'depression' until it was established that the participant and the researcher had a common understanding of the ASL sign used by the participant to express depressive symptoms. The participant was then asked what sign he or she uses to represent these feelings (e.g., if an ASL sign that expresses and represents a phenomenon is unknown, words are spelled). When clusters of depressive symptoms were described, the researcher asked what sign is used to describe the clusters. Interviews lasted 30-60 minutes, and continued until saturation was attained (i.e., no new information emerged from the participants).

Each participant was interviewed three times, as suggested in the literature (Crist & Tanner, 2003; Fleming et al., 2003). The first interview introduced the researcher to the participant's life history, the second expanded on important issues from the first interview, and the third focused on the participant's reflections of the researcher's interpretations. The researcher made brief notations of participant gestures, facial expressions, body language, and any disparities between what was being said and how it was said. No participant was interviewed more than once a week.

There were occasions in which the certified interpreter and the researcher differed in their understanding of the participant's response. In each case, the interview was paused, a brief discussion took place between the interpreter and the researcher, and the participant was asked to repeat his or her response. The interpreter and researcher usually agreed on the interpretation the second time; on the rare occasion that the interpretation was still in doubt, the videotape was reviewed by two interpreters and the researcher.

Understandings are affected by the present moment, and watching/viewing and listening to the ASL words and voice recordings are key components of analysis (Fleming et al., 2003). Each interview was recorded in its entirety. This followed the philosophy of Gadamer (Gadamer, 1975) that describes conversations as being moments of history that are subject to interpretation; recording allowed the researcher to transcribe verbatim and then analyze through reflection by reading the written text while listening to the recorded conversation. The researcher also made brief notations during the interview, including participant word choice, body language, facial expressions, and any disparities between what was being said and how it was being said. This enabled the researcher to

further explore disparities on subsequent interviews. The researcher transcribed the video recordings of the interviews into Microsoft Word, and included all notations made during and after the interviews.

Journals and Reflections

Ongoing reflection provides a coherent way to carry out analysis and to synthesize the descriptions of the phenomenon (Fleming et al., 2003; Wiklund et al., 2002). Rather than attempt to bracket or set aside one's pre-understanding as in phenomenology, the theoretical perspective of hermeneutics views that isolating prejudice is impossible. In order to reach mutual understanding, one must be aware of pre-understanding (Annels, 1996; Fleming et al., 2003; Gadamer, 1975; Van der Zalm & Bergum, 2000) and forestructures (e.g., pre-understanding, assumptions, knowledge, bias, beliefs) and incorporate this into the analysis and interpretation of text.

Self-reflection was done prior to each interview, in order to identify the researcher's pre-understanding and prejudices (e.g., knowledge, awareness, experience, beliefs (Fleming et al., 2003)) of deafness, culture, and depressive symptoms. To move beyond pre-understanding, the researcher used journaling and reflection during and after all interviews and analysis. Reflection also included the researcher's role of self during the interview.

Data Quality

The constructs being examined must have similar meaning and cross-cultural relevance (Pollard, 2002). The researcher must have an appreciation or sensitivity to the unique culture under study (E. Jones et al., 2006; P. Jones, Lee, Phillips, Zhang, &

Jaceldo, 2001; Pollard, 2002). Consideration for culturally sensitive research must include functional equivalence, which is defined as the ability of a concept to perform or elicit similar responses in two or more cultures (P. Jones et al., 2001). Engaging in dialogue with culturally Deaf adult participants necessitate interacting in the participants' preferred language of choice. Phrases and terms used in the dialogue must be meaningful to the population (Pollard, 2002). Although the researcher is somewhat fluent in ASL, she used two certified interpreters to ensure that concepts were accurately being discussed and described. The interpreters did not voluntarily offer direction or alternate word usage without conferring with the researcher. The second certified ASL interpreter reviewed several randomly selected videotaped recording from each participant interview to ensure that the primary interpreter was consistent and accurate in her translations.

Analysis

Analysis is ongoing during the interview process (Annels, 1996), and allows for understanding through engagement of text (i.e., dialogue and transcriptions). During analysis there is continual movement from the whole of the experience to the various parts or phrases, and back to the whole. Language is interpreted then transformed into meaning, and through continued engagement with the narrative (i.e., written record of interviews, observations, and reflections), the researcher searches for shared meaning among participants. Shared meaning is attained by examining the language for patterns and themes (Priest, 2002).

Understanding is inexorably intertwined with interpretation (Annels, 1996), and language is the means to understanding. Hermeneutic analysts maintain that

understanding is possible through relationships (Fleming et al., 2003). Consciousness is also inseparable from history, therefore understanding can only be possible with awareness (Fleming et al., 2003); to increase her awareness during the interviews and subsequent data analysis, the researcher continually used reflection to heighten her awareness of her own pre-understanding. Continued reflection also enabled the researcher to consider the nature of her relationships with each participant as they shared their individual stories.

Text was generated for each interview through word-for-word transcription and researcher notations (e.g., observations and reflections); the first set of interviews was analyzed before engaging in further interviews. The researcher read the text while simultaneously reviewing the recorded interviews, and then selected phrases or statements that seemed to represent a concern for the participant to be further discussed in the next interview (e.g., this facilitated entry into the hermeneutic circle of mutual understanding). Once all text had been generated, text was read and re-read to obtain a broad understanding and meaning of the experience (i.e., the whole). Each individual sentence was then examined for further meaning (i.e., the patterns or parts). In order to widen understanding, each sentence was next considered within the context of the broader understanding (i.e., parts to whole). Finally, passages that seem to best represent the meaning of depressive symptoms among culturally Deaf adults are reported.

Rigor

Qualitative research is not generalizable; however, the findings may allow the researcher to develop a theoretical understanding of the phenomenon under investigation.

Rigor helps to assure the legitimacy of the research method as science. Quantitative researchers refer to rigor in terms of establishing validity (i.e., evaluating the soundness of the research) and reliability (i.e., consistency, obtaining the same results with repeated tests). To ensure that the researcher stays true to the scientific method, most qualitative researchers speak of rigor in terms of trustworthiness (Sandelowski, 1986). The general purpose of qualitative research is to reconstruct an experience and gain understanding; therefore the legitimacy of the research study is evaluated in terms that reflect mutual understanding, such as trustworthiness. This is discussed next.

Trustworthiness

In hermeneutic interpretive phenomenology, numerous terms have been used to describe assurances of trustworthiness (Clarke, 1999; Fleming et al., 2003; Sandelowski, 1986; Streubert-Speziale, 2002). There are occasional references however, to validity and reliability in qualitative research. There are various terms used in qualitative research such as credibility (i.e., evaluating believability) and authenticity (i.e., that essentially point to trustworthiness). While terminology may vary depending upon the framework used to guide the method, qualitative studies assure integrity of the method by examining how decisions were made in analysis, why decisions were made, if analysis clearly reflects the experience, and if participants can recognize the experience as retold by another (Fleming et al., 2003; Laverly, 2003).

Methodological trustworthiness is assured by striving for objectivity and neutrality, by remaining true to the narrative and through either rigorous bracketing or clear identification and incorporation of pre-understanding into the narrative. Rigor of the

scientific method is assured if the descriptions of the phenomenon or experiences are recognizable to participants, and if narratives clearly reflect the true essence of the phenomenon. Phenomenologists use bracketing to help establish rigor, whereas hermeneutic researchers identify their pre-understanding and repeatedly consider how this may affect interpretation. Their interpretations are then shared with the participants to evaluate mutual understanding. The researcher considers whether he or she successfully entered the hermeneutic circle of understanding and the fusion of horizons, metaphors for mutual understanding. Mutual understanding has occurred if the researcher has successfully captured the participant's concerns and meanings.

Following the method proposed by Fleming et al. (2003) trustworthiness was judged by auditability, credibility, confirmability, and objectivity. Auditability is demonstrated by the researcher's written report showing documentation of decisions that were made during analysis (e.g., why a particular interpretation was made and how pre-understanding might have affected the interpretation), and by discussing document decisions during phone calls with the research mentors. Conversations with a researcher whose program of research is depression helped to identify and define concepts that were discussed during the interviews; conversations with a consultant whose program of research is the Deaf further helped to refine the concepts identified. During the earlier interviews, the researcher was challenged by her nursing background. Several questions directed toward participants reflected her concern for the participant's health, and undoubtedly affected earlier interpretations. As she continued to refine her interview skills, she was able to more fully engage in the participant's story instead of being

distracted by health care issues. This improved interpretation and decisions made during analysis, and continued phone calls with the dissertation committee furthered the improvement.

Data quality was first addressed by multiple reviews of the DVD-recorded interviews. The second certified interpreter's role was to review the accuracy of the primary interpreter's ASL signs to the participants and the spoken English translation of the participants' signed ASL. This occurred for every initial interview with a participant, and for any subsequent participant interviews in which either the researcher or the interpreter questioned the accuracy of translations. Additionally, most of the DVDs were sent to two dissertation committee members for review; this consisted of evaluating the researcher's interview techniques, the accuracy of the interpreter's ASL skills and spoken English translations, and the researcher's interpretations of participant body language and facial expressions.

Credibility is illustrated by including numerous quotations from the participants that reflect their perspectives. Communication with the researcher's committee members helped to ensure that the descriptions of depressive symptoms and the culture of the Deaf are recognizable and therefore credible. A one-page summary sheet of the shared meanings and central concerns was given to some of the participants, and also someone considered an expert in the Deaf culture. Their recognition of the meanings and concerns as reflective of the experience of depressive symptoms further established that the findings are credible.

Confirmability (i.e., ensuring that mutual understanding and fusion of horizons was attained) was addressed by conducting three interviews, sharing the interpretations with participants during subsequent interviews in ASL, and continuing interviews until saturation was achieved. Recruitment continued until the stories and experiences of the participants began to overlap. The first and second interviews for each participant continued until there was no new content emerging. Confirmability was further established by interviewing the participants in their language of choice (ASL), using certified interpreters, and having one investigator conduct all interviews. Confirmability was also addressed by asking the participants to review the summary sheet of shared meanings, then asking for their thoughts as to accurate reflection of their experiences.

Objectivity (i.e., faithfully representing texts) may never be achieved, as each reader of the written report experiences their own interpretation based on their own horizon (Fleming et al., 2003); however, the researcher strived for objectivity by continued reflection during interviews, transcription, and subsequent interpretation. There were occasions in which the participant used an ASL sign to indicate an emotion such as "afraid", which was not accompanied by facial expressions used to connote severity; the interpreter however voiced the word as "terrified". In such a case, the researcher and interpreter discussed the terminology and ASL sign, and returned to the participant for clarification. This furthered the efforts at establishing objectivity. The researcher strived to address objectivity while transcribing from signed ASL and the interpreter's voice into Word format, which initially caused some difficulty. During numerous conversations it was clear that the interpreter was voicing words that were not coming from the

participant, such as "you know", "like", and "um". To maintain objectivity, it was noted during transcription that these were not coming from the participant. Finally, objectivity was addressed by reading and re-reading the narratives while reflecting on the researcher's own pre-conceptions, and allowing the participants' stories to unfold.

Summary

Chapter III has presented the method for the proposed study. The study method was described, the role of the interpreter was identified, and procedures for human subject protection were listed. The sampling procedure, the process of data collection, data analysis, and the method of ensuring rigor were delineated. Chapter IV will discuss the study findings.

CHAPTER IV: FINDINGS

This chapter describes the study setting, offers a portrait of the participants, and presents the findings and analysis. The portraits were generated from comments made by the participants and from the author's perceptions formulated during interactions with each individual. Analysis was derived from commonalities among participants as they expressed emotions and related their concerns and experiences. Quotations and exemplars are included to support and illustrate the patterns of individual concerns, shared concerns, and shared meaning. Signs in American Sign Language (ASL) that represent depressive symptoms are described.

Study Setting

The study was conducted in Reno, Nevada, which rests on the Eastern slope of the Sierra Nevada mountain range. Reno is a rapidly growing city, with a population of approximately 330,000, and is the largest city in the northern half of the state. Although some of the participants describe Northern California as their legal residence, all identified Reno, Nevada as their social hub and point of health care access. Several organizations provide services to Deaf community members, such as the Deaf and Hard-of-Hearing Advocacy Resource Center (DHHARC), and University of Nevada Reno Disability Resource Center. There is an informal coalition of certified ASL interpreters who serve Northern Nevada and Reno but no hospital or health care center in the Reno area has a formalized arrangement with any interpreter. Two participants left Nevada shortly after being interviewed for this study, as they were discouraged by the lack of health care resources and supportive services. As one participant described the Deaf

community, in the past three years the number of Deaf adults have dropped by half (now approximately 250 residents) because there is a dearth of services for Deaf.

The Research Participants

Nine culturally Deaf adults participated in this study. To insure confidentiality of the participants, some defining personal characteristics or circumstances have been altered. All participants are identified by pseudonyms to ensure anonymity. Participants ranged in age from 21 to 65. More females (N=7) volunteered than males (N=2), and more were non-Hispanic whites (N=7). Every participant had completed high school, two had a terminal 4-year college degree, and two have graduate degrees.

Because 90% of deaf children are born to hearing parents (American Speech-Language-Hearing Association, 2004), it was not surprising to learn that every participant in this study was born to hearing parents. Etiologies for hearing loss included infection or high fever, trauma, and possible medication side effects; for several participants the exact date and etiology of hearing loss was never known. None of the parents of these participants learned to communicate in ASL while their child lived at home. Every participant made vocalizations during the interviews, although not all vocalizations were clearly understandable.

The educational level ranged from completion of high school to graduate school. Each participant spent a portion of time in a hearing-oriented educational system, where spoken English and speech-reading was emphasized and the visual language of ASL was not introduced or was discouraged. Although every participant had graduated from high

school, the level of English reading comprehension varied, as noted while obtaining written and signed consent.

The study goal was to explore depressive symptoms among members of the culturally Deaf community; any participants who were willing and able to describe their experiences with depressive symptoms were invited to participate in the study. Several participants had previously been diagnosed as depressed, and one participant was under the care of a provider for depression during the study. The largely White (i.e., Caucasian) population of the Reno community is reflected.

Portraits of the Participants

The following section provides a description of each participant in the study. The purpose of the portraits is to contextualize the feelings, emotions, and depressive symptoms within their life experiences. The portraits also help to illustrate the commonalities of their lives as well as their unique differences.

Each participant was assigned a pseudonym. Defining characteristics and locations are intentionally excluded from the narrative to protect the participants' anonymity. These portraits are based in part on the statements made by the participants during the interviews. Each participant helped to create their profile by what they elected to share and what, if anything, they opted to withhold. The researcher's perceptions and impressions, which stem from repeated interactions with each participant adds to each portrait.

Brigid

Brigid described her early life as sad, often feeling lonely and isolated. She lost her hearing in infancy, but is unsure as to the etiology of her deafness. No one in her immediate family learned how to communicate in ASL, so she never felt a sense of understanding within her family. She remembers wanting to be like her sister, who was hearing, and had a boyfriend. Even though she related that her sister was nice, Brigid recalled feeling hurt and left out by her sister. School was difficult, as Brigid knew no deaf children, and was ignored by the hearing children. Brigid described a few schoolmates as being nice to her, “one boy – spastic – was nice to me”, and some smiled at her. She painfully recalls not going to dances or being invited to parties.

Encounters with hearing people have often left Brigid feeling embarrassed or frustrated. She has also felt frustration directed at her by hearing people, especially when she has had to ask for assistance in a grocery store or shopping center. Brigid’s impression of hearing people is that they are often impatient with her or mad at her, which they demonstrate by making faces. Her childhood teachers emphasized using voice, but Brigid related that hearing people are not patient when she tries to voice. When she has felt sad for an extended period of time, Brigid recalled feeling tired, and having no interest whatsoever in anything. She found no pleasure in eating, and often had to force herself to eat.

Brigid’s life began to change for the better after she met her husband, who is also Deaf. As she was educated primarily in an oral program that emphasized voice and speech-reading, Brigid identified that her ASL signs were not nearly as fluent as her

husband's. She related that her ASL skills improved greatly after she began to see more of her future husband.

Brigid describes herself now as happy. She is active in the Deaf community, and enjoys going to Deaf community dinners and social events. She and her partner have hearing children, and all the children are fluent in ASL. She also enjoys working on her computer, and is quick to praise the technology that enables her to connect with other Deaf people. Brigid enjoys her work environment, where she has contact with some other culturally Deaf adults and also gets along with some of her hearing colleagues.

Although she has a sense of community now, Brigid expressed fear of the future. She wondered aloud what might happen to her if her husband should die. Brigid feels confident in her work environment, enjoys her Deaf community, has children who are fluent in ASL, but fears her life situation if she should be widowed.

Ciara

Ciara described herself as lonely and scared. She was born deaf, whereas her siblings are hearing. She was initially sent to a public "hearing" school, but later attended a residential school for the deaf. She has no contact with her parents or siblings now, and does not even know if they are alive.

Ciara was married for many years to a Deaf man but was divorced several years ago. She has two grown children, and both were born deaf. While she is very happy for her children and their success, she laments their moving far away to pursue their professional opportunities. She contemplates moving, to be in closer proximity to her children, but immediately voiced her fear at finding employment and leaving a familiar

area for an unknown. She currently rides the city bus to work, and worries about having to learn her way around a new area. Ciara also quickly added that each child is in a relationship, and she worries that she would be an imposition or even left out.

Ciara is worried about her current employment, as the company she works for is closing. She expressed fear of finding a job, not having enough money, and being lonely. Ciara holds out hope that her children will return to the Reno community and she will not have to feel alone any more.

Casey

Casey lost his hearing at three months of age as a result of infection and fever. He was sent away to a residential school at the age of six, and remembers crying, feeling afraid, and being comforted by the teacher in the classroom. He also recalls all the kids teasing him, which continued until he was able to communicate in ASL. There was no common means of communication in the family, and Casey had no siblings.

Casey's parents divorced when he was three; Casey describes his father as really nice and wonderful, although Casey was not able to spend much time with his father. Weekends were spent with Casey's mother. Casey's mother was an alcoholic, and he related witnessing frequent fights and arguments between his mother and her various lovers. During these fights, alcohol was being used to excess. Casey recalls that many times he was sent to his grandparents for the weekend or even an extended period of time; he also recalls living with his mother's sister for several months at a time.

As Casey was bright, the expectation of his family was that he would obtain a four-year degree. Because of what he described as family issues, Casey elected not to

continue on to university. He moved out on his own and settled in an apartment; he described his life away from the family home as free and stressed that he didn't have all the fighting and ups and downs. Shortly after moving out of the house, Casey's mother did commit suicide. Casey expressed regret, saying that if he were living at home, he might have been able to help his mother.

He started a serious relationship with a hearing woman, who he described as his sweetheart. He taught her to communicate in ASL and she became fully fluent. He wanted to marry his girlfriend but his mother disapproved of the relationship. They did eventually marry.

Casey divorced his first wife, but expressed that they still have a good relationship. They had children together, and also adopted a number of foster children including one deaf child. Casey's wife taught the child, but his other children never learned to sign. Casey remarried 26 years ago, and described himself as happily married to a Deaf woman.

Eileen

Eileen described her life as having three stages: she defined stage 1 as before she became deaf, the second stage is her transition from hearing person to Deaf person and the third stage is living life as a Deaf person with a Deaf personality. Eileen's perception of herself before the hearing loss is that she was always very excited and happy. She had one older sibling.

The second stage of Eileen's life was mid-adolescence, initiated by a traumatic physical event. She is unsure whether her deafness stems from physical damage or

medications related to treatment of the physical trauma. After the trauma, Eileen returned to her hearing school, and attempted to continue education without benefit of special services or assistance. Friends and teachers wrote notes and offered explanations of problems and concepts, and Eileen put much energy into learning to lip-read. She described feeling frustrated, self-isolating, feeling low self-esteem, becoming quieter, and feeling nothing like her former self. She also described this stage of her life as losing her hearing personality and she sometimes felt like giving up. After spending one month at the hearing school as hearing impaired, Eileen left her school and elected to stay home for the following four months. She then focused her energy on preparing to take an examination in lieu of coursework for graduation.

Eileen related that the third stage of her life involves becoming a member of the Deaf culture. She had an occasion to observe people communicating in ASL, which then prompted her to learn ASL:

“I was shocked when I saw that! I thought, wow, how cool! Communication – full communication – that’s possible!” “The world just opened up for me again, and I was able to communicate fully and I was able to interact in groups and with other people and my self-esteem improved, and I became, it was like the first stage and the third stage, I was the same person; I was excited, I was happy again – I felt like I was my old self again, you know?”

Eileen has become very active in the Deaf culture and community. She elected to pursue advanced education in Deaf academic settings. She works with other Deaf adults, she teaches ASL to both hearing and deaf individuals, and she frequently places herself in a position to advocate for deaf children and deaf adults who do not have a way to communicate. Eileen expressed pride at being a Deaf adult with what she refers to as her

“Deaf personality”, and asserted that her lifelong goal is to help other Deaf people succeed.

Eileen desires to find a mate, get married, and raise a family. She described herself as too busy with her career now to actually meet a compatible partner, and also expressed frustration with dating. She wonders about the possibility of dating a hearing man but expressed that hearing men are afraid of her because of the differences in communication. She related that there are not many opportunities to date and meet new people right now. She expressed her reluctance to date a Deaf man because she believes that most Deaf men are not well-educated. She described herself as a very bright and successful woman, and therefore worries that she could never find a Deaf man who would be intellectually stimulating. She related that until she finds a match, she focuses on career, friends, and her goals.

Joan

Joan has no knowledge of how she lost her hearing or at what age; she proposed that she may have been born deaf or she may have lost her hearing at an early age. She believes that she was first examined for deafness when she was a toddler, and remembers undergoing tests to evaluate the etiology of deafness. Joan was also evaluated by teachers, and eventually began education in oral programs at the age of four.

Joan’s parents did not know ASL. Joan taught herself the ASL alphabet from text books, but stressed that the only communication around the home was through gestures. Joan had no siblings and did not know any other deaf people. She remembers trying to

communicate with other young children through gestures, and related that she didn't start talking until the age of 8.

When Joan was six, her mother died, and she was sent to live with her mother's parents. She remembers visiting her mother in the hospital, and knew that her mother was very ill. Joan did not know of her mother's death for two years. Joan related that she had not been told about her mother's death based on the advice from the local preacher.

Joan described herself as being a bad girl and getting into trouble as an adolescent and young adult. She had several suicide attempts during this time period. She eventually sought psychiatric help, and her life began to improve. She did complete her college degree.

Joan met her Deaf husband when she was 26, and they have been married for 26 years. Joan has had a successful career while also working with Deaf children and adults. Joan and her husband work together, and the business opportunity has helped them to meet other members of the Deaf culture.

Although Joan loves her husband, she expressed that she is looking for a new way of life. She described herself as wanting independence, and expressed fear that her husband will not understand this. She volunteered that if her husband found a good companion, then she could have her own space. She related that she wants to stay married, but also wants more independence than she now experiences.

Maire

Maire described herself as angry or sad all the time. She was born deaf, and had one sibling who was hearing. She recalls feeling happy when she was young, and

suggested that the sadness began when her sibling left home to go to school. This left Maire feeling alone, sad and angry.

Maire feels that hearing people leave her alone and ignore her. At work, she eats alone and often watches others going out together after work; she lamented that hearing people never ask her to go anywhere. Her boyfriend picks her up after work, which she enjoys. She loves her boyfriend very much. Sometimes they enjoy socializing with other deaf people, when Maire is not too tired to go out and socialize.

Maire and her deaf boyfriend want to get married and have deaf babies. She wants deaf babies who can sign. She volunteered that if she has a deaf husband and deaf children who sign, she would never have to be alone. Maire understands that her mother is against a marriage or pregnancy, and frequently tells Maire that she cannot take care of a baby. She feels happy with her boyfriend and hopes her mother will soon be happy with Maire's marriage.

Nora

Nora lost her hearing when she was five, the result of high fever and antibiotics. Her parents divorced immediately after Nora's hearing loss, and she felt that her father blamed her for the divorce. Nora says that before she lost her hearing, she would eavesdrop on her parents during their arguments. After losing her hearing, she was aware that her father was moving out but did not understand what was happening. The lack of communication between Nora and her parents caused her to feel afraid when her father left the household.

She was sent to an oral school at the age of four, and quickly excelled because of what she described as her intelligence. She learned to read within her first six months of school, but she feels very inept with life beyond her books. Nora expressed that she has never doubted her intelligence and feels quite successful academically. She related that she has a more difficult time applying what she learns from books to interacting with people.

Nora described herself as excellent at speech-reading, but related that she often misses little nuances that cause her to lose the entire theme of a conversation. She did not learn ASL until she was a teenager, and communicating in ASL has restored Nora's ability to fully converse. Many of Nora's friends are culturally Deaf, and she has embraced her Deaf culture. She related that her father does not sign, which leaves her feeling stupid and with a deflated self-esteem. She is unable to have a full conversation with her father, which causes her to feel like she has something to prove.

Nora volunteered that she has self-mutilated for years, which she proposed, allows her to cry. Last year, she was at a low point and she attempted suicide. She and her father argue frequently. Many arguments center on Nora's desire to continue her education and to pursue working with the Deaf. She is now essentially estranged with her father because of his continued disapproval, but also because she feels he favors her siblings over her.

Nora is currently being treated for depression; she takes medication and sees a counselor. She related that since beginning medication, she has more good days than bad. She struggles with her identity. She described herself as very self-critical and insecure.

Nora has some health conditions which leave her fearful of even falling asleep. She related that the less she sleeps the more afraid and paranoid she feels; reading or writing in her journal helps her to relax. Nora frequently has three or four nights of horrible nightmares; these cause her to wake up with a startle, and she feels sweaty, her heart is racing, and she cannot catch her breath. More often she has a difficult time falling asleep. These nightmares and sleep disturbances have occurred since she was a young child.

Between the first and second interview with Nora, she visited friends in another state. She related that although she came down with a horrible cold, she spent much time reading and just being with friends. She described this period as nice because she finally felt like her true self. As a result of this positive experience, she is looking into the option of moving to another state. She does express that she is excited but also scary, because she does not know how to take care of herself. She quickly imparted that she is also very capable of taking care of herself if she can get past her insecurities. Nora considers this decision as a conflict that illustrates her internal battle.

Sean

Sean lost his hearing at the age of five, and thinks this was from ear infections and medications. He described himself as having grown up in a hearing world. He had a hearing sibling, dated hearing women and was able to speak well. Sean spent much of his early life feeling like people “never understood him.

Sean described himself as bright, and eagerly began public college. During his freshman year, his grades slipped and he stopped caring. At that time, he did not want to eat, and wanted to die. He also felt no hope for the future, because he felt that nothing

would ever change for the better. This caused Sean to think about suicide, and he did attempt suicide during college. His parents felt that college was too stressful for Sean; he took a break and then transferred to a different college. During college, Sean also became an avid kayaker, and hoped to pursue the possibility of being a river guide. He applied to different companies but related that no company would hire him because of his deafness.

Sean's first contact with another deaf person was in college, when he met his wife. He related to his wife because she also did not lip-read, was lonely, educated, was going to college, and had no previous contact with deaf people. They have been happily married for many years. They have family members now who are fluent in ASL and are active in the Deaf community.

Susannah

Susannah described herself as a single college student and part-time ASL tutor. Her parents had divorced years earlier, and Susannah lived with her mother. Her brother died when Susannah was young, in a traumatic event that Susannah witnessed. Susannah blames herself in part for her brother's death, although she articulated that she could not have done anything to prevent it.

She lost her hearing as an adolescent, as a result of an illness. She recalls the hearing loss as a time of being terrified, as one minute everything was fine, and then next minute her life was significantly altered. She described this time as losing her dreams, feeling like no one could help her, and her world becoming increasingly small. Susannah was criticized by teachers and physicians and told that she wasn't trying hard enough. Susannah remembers seeing one doctor after another, as the hearing loss was

investigated. Her mother took on the role of speech therapist. Susannah wanted to learn ASL, and she recalled that she kept making this request. Her mother and her doctors recommended against this. She recalls feeling full of anger and began to self-mutilate.

During her early college years, Susannah remembers having suicidal thoughts, and sought a counselor. She has attempted suicide and has reached out to different people for help. She described feeling the need to act like a hearing person, which caused her to feel frustrated and angry.

Susannah has the goal of being a professional working woman. She proudly identified that her grade point average has been very high, even though she has taken many hard courses. She has faced what feels like discrimination as she has tried to continue with her professional growth. She described herself currently as angry, she is not sleeping, she is unable to focus, she cries frequently, and she has lost all interest in life. She related that her anger is directed toward the entire government system.

Although she identifies herself as culturally Deaf, Susannah also related that she does not have many close Deaf friends. She explained that other Deaf people tell her she sets the bar too high, and that because of her extensive education she does not fit in very well with many Deaf adults. Susannah declared that most of her friends are hearing. She enjoys contact with Deaf adults, and tutors Deaf adults and children. She imparted that because she enjoys reading scientific journals, which most Deaf cannot relate to, she does not feel she has many common interests with Deaf adults. Susannah admits that this leaves her feeling lonely, isolated, and tremendously sad.

Summary of Participants

The portraits of the participants offer a brief glimpse into their lives and relationships with others. This helps to contextualize their experiences with depressive symptoms. Contemplating each participant's uniqueness helped the researcher to also appreciate the commonalities among the participants, which ultimately enabled the recognition of patterns to individual concerns, shared concerns, and shared meaning that slowly emerged from dialogue and reflection.

Shared Meaning, Shared Concerns, and Patterns

The following narrative contains a subjective report of experiences filled with the teller's own perceptions, and the researcher's reflections and interpretations. The narrative incorporates the dialogue content with the researcher's personal reflections, journaling, and pre-understanding. Commonality of experiences, shared concerns, and shared meanings are identified and described, and to provide illustrations of these, excerpts from the hermeneutic dialogues are included.

Data analysis resulted in four abstractions of shared meaning, which describe the participants' live experiences and depressive symptoms. Each abstraction is composed of shared concerns, and the shared concerns stem from commonalities of experiences. The abstractions of meaning are introduced and briefly described:

- *Meaning # 1: Feeling depressed.* This is defined as feeling physical and emotional symptoms of depression, and communicating depressive symptoms in ASL signs, gestures, and words. The shared concerns included (a) how depressive symptoms feels physically and mentally and (b) the signs and gestures used to

communicate depressive symptoms. Physical symptoms included fatigue, appetite change, and body aches. Common mental symptoms described were anger, low self-esteem, crying, loss of interest, feeling guilty, and not being able to concentrate. Several ASL signs were used to connote depression.

- *Meaning # 2: How did I get depressed- emotional chaos in my life.* This is defined as experiences of childhood, adolescence, and adulthood that led to depressive symptoms. Two shared concerns emerged (a) feeling different and isolated and (b) feeling abandoned. Common experiences included feeling different from other family members, feeling different from hearing children, feeling limited because of differences, feeling isolated from friends, feeling excluded and isolated from conversations, feeling abandoned by parents, friends, or co-workers, and feeling abused.
- *Meaning # 3: reaching out.* This is defined as learning to walk in the Deaf world while also navigating the hearing world. Two shared concerns were observed (a) reaching out to others in the hopes of being heard and understood and (b) reaching for the future. Common experiences that continually reinforced the lack of social support and exacerbated depressive symptoms included concerns when reaching out to interpreters, difficulties reaching out for health care, and unsuccessfully reaching for safety. Reaching to the future meant contemplating the future, relationships, and feeling afraid for the future.
- *Meaning # 4: I am Deaf – I am not broken!* This is defined as identifying oneself as a member of the Deaf culture. Two shared concerns were noted (a) feeling

proud to be a member of the Deaf culture and (b) promoting the Deaf culture.

Common experiences associated with acceptance into the Deaf culture included forming important relationships with other Deaf adults, and improved self-esteem; ultimately membership in the Deaf culture helped to counter the social isolation and even depressive symptoms. Teaching ASL, tutoring deaf/Deaf children and adults, and teaching about the Deaf culture were common ways of promoting the Deaf culture.

The following section describes four shared meanings. Each meaning is comprised of several concerns that were expressed by most or all participants. The concerns stemmed from the experiences related by the participants. Excerpts from participant narrations are included to illustrate the concerns and experiences. The discussion begins with the first abstraction, what it means to feel depressed.

Meaning # 1: Feeling Depressed

The participants described their experiences with depressive symptoms as times of great emotional distress, and often associated with physical distress and discomfort. Only Susannah, Nora, and Joan have been formally diagnosed with depression; Susannah and Nora are currently under treatment (e.g., medication and therapy). Eileen believes that she has not ever been depressed, but then described her feelings and emotional responses to some life events and proposed that perhaps she had been depressed. There was much variation in how the participants expressed their depressive symptoms, including specific signs in ASL, gestures and facial expressions, and self-injury. Two

shared concerns were noted: how depressive symptoms feel, both physically and mentally, and how they are communicated. These concerns are elucidated below.

How Depressive Symptoms Feel Physically and Mentally

When asked to relate what depressive symptoms feel like, the participants described feeling angry, and some had a difficult time separating feelings of anger from feelings of sadness or depressive symptoms. Depressive symptoms were described as feeling like nothing held their interest any more, feeling unable to make decisions or feeling confused, feeling low self-esteem, feeling guilty, feeling sad, and crying for extended periods of time. Long stretches of depression left some feeling depleted or emotionally exhausted. Several participants spelled the word *rumination* and expressed that this contributed to their waking up in the middle of the night and with difficulty falling asleep.

For some, the experience of living with depressive symptoms was associated with a mixture of intense feelings and emotions that were inseparable. When Maire described her sadness, it was always in conjunction with her feelings of anger, and often communicated tearfully. Joan described her early depressive symptoms as a combination of feelings such as anger, frustration, resentment, humiliation and low self-esteem; her phrase for this collection of feelings was 'a black cloud in my mind'. Joan attributes her depressive symptoms now to feeling trapped, feeling indecisive, and looking for a new way of life; Joan disclosed she has a difficult time separating her reactions, which leaves her feeling overwhelmed. She also related that feeling overwhelmed in the present triggers past hurts, anger, and depression. Nora's depression feels:

“A sadness, an overwhelming feeling of, kind of boiling up inside, it's just this festering boiling going on. On the surface, you know, it seems fine, but you know, really, deep down inside it just feels sad, overwhelmingly scary....sometimes, really....terrifying.”

Depressive symptoms were often associated with physical discomfort and physical manifestations such as sleep disturbances and appetite changes. Susannah wanted to stress to the researcher that depression hurts physically as well as mentally. Ciara and Sean related that although they frequently felt tired, they were unable to sleep; they often used alcohol in an attempt to sleep and Sean relies on sleeping pills during periods of depression. Maire described taking a long time to fall asleep, or not sleeping. When she feels depressed, Ciara also feels tired and her body aches. Brigid associates her depression with feeling tired all day and not sleeping.

Depressive symptoms were often associated with a sense of being depleted, feeling devoid of the energy to do even easy tasks. Susannah and Sean related that depressive symptoms left them without energy, and prevented them from accomplishing their goals and dreams. When Joan has felt depressed, her mind races and she cannot stay focused; she relates that her mind often takes her back to depression of years ago.

Susannah communicated that her depressive symptoms feel:

“Horrible. I couldn't sleep, I couldn't focus, I lost all interest in life, I kept crying, I was angry all the time, I had no desire to be with my friends or even talk to my friends, I stayed home alone, I isolated, I didn't even clean my house – normally I like to have a clean house, but I just didn't even find the energy to do that.”

Several related experiencing a change in appetite during a period of living with depressive symptoms. Brigid described not being hungry, and Joan related that she noticed a significant increase in her appetite when she felt depressed. Sean described

feeling depressed in college, and remembered not being hungry, not eating, staying in his dorm room rather than going to the dining hall for a meal. Joan's appetite is the opposite when she feels depressed; she explained that she cannot stop eating.

Several participants described physical symptoms and immediately identified these as manifestations of their depressive symptoms. For others, physical symptoms were listed but never attributed to depression itself. In these cases, the participants had sought relief from health care providers. When describing how they managed their physical symptoms, the responses included doing nothing, not knowing what to do, taking sleeping pills, using pain pills, and alcohol. For some, suicidal thoughts and gestures seemed to offer the best way to cope. Suicidal ideology is further discussed below.

Feeling suicidal. Six participants described suicidal thoughts or attempts.

Although Ciara has never attempted suicide, she expressed that she thought it would be easy. She was also quick to identify that she would never kill herself now because of her daughters. Casey outlined feeling suicidal during a particularly frustrating and hurtful time in his life, but has never attempted suicide. When Susannah felt hopeless and overrun with emotions she considered suicide. She recounted driving over a mountain pass one day and thought about driving off the edge. She also tried to slit her wrists when she felt she had no other options. Susannah offered a narrative of her feelings before her attempted suicide:

“The emotions are so strong, that I just can't move my body. When I am at my worst, my scare of self-injury actually hurt. My emotions are so overwhelming that my body doesn't respond. I look for a release. I can't

cry. Sometimes I just want to hurt physically so I self-mutilate – it helps me focus on my physical pain and then I can cry.”

Sean was happy about college at first, but then began to feel hopeless. He tried to overdose, relating that he just didn't care and he wanted to die; he felt like his life would always be the same and nothing would ever change.

Joan attempted suicide. She chronicled feeling the black cloud over her head and she began to think about suicide. When she felt particularly overwhelmed with emotions, she cut her wrists. She saw a therapist, which she did not find helpful. Joan again tried to commit suicide by drug overdose several years later, when away from home. She was subsequently hospitalized and diagnosed with depression.

Nora described feeling overwhelmed with emotions. She felt frustrated and had no hope for the future. She also tried to cut her wrists. She tearfully elucidated her experience:

“I really did try and slit my wrists, and, you know, I started cutting and I just, I thought to myself, what the hell am I doing? I can't - this is crazy – I can't do this.”

Suicidal ideation and attempts were manifestations of hopelessness and intensity of emotions. Attempts at therapy or health care interventions were unsuccessful at helping move through the painful or difficult times. For some participants, their suicide attempts were physical expressions of the emotional pain, hopelessness, and depressive symptoms. The following section outlines the signs and gestures used by the participants to describe their depressive symptoms.

Signs and Gestures Used to Communicate Depressive Symptoms.

Five participants used the same sign in ASL to represent this cluster of feelings (i.e., running the middle finger of each hand down the front of the chest). When this sign was used with Maire, Ciara, and Brigid, it appeared to have no meaning. Maire related:

"Angry - sad all the time, day - night, no difference between angry sad; same thing day night sad angry, cry all time, afraid."

When Maire was asked if she had a sign to represent these feelings, she signed in a unique way (e.g., two hands coming up from the stomach toward chest, then signing sadness and tears) that was not recognized by any of the other participants or interpreters. The interpreter also finger-spelled the word *depression*, to which Maire shrugged her shoulders and indicated that she did not understand. Ciara described feeling sad and angry, scared, isolated, lonely, afraid, frustrated, and had thoughts of suicide; the sign she used to identify her cluster of feelings (i.e., one fist moving down in front of chest) did not have the same meaning to any other participant. She also indicated no understanding to *depression* (e.g., finger-spelled) or the sign used by the majority of participants.

Brigid understood the word *depression* when it was finger-spelled. She used one sign to represent feeling isolated, alone, sad, frustrated, hurt, and feeling blamed; this sign was unique to her (i.e., fingers on each hand making the sign of small 'd', then running this down front of the chest). When other participants were asked about Brigid's sign for depression, Ciara and Maire indicated no understanding. All other participants identified this sign as not ASL but a different version of sign language (e.g., See-sign - signed exact English).

In addition to using one ASL sign for depression (e.g., middle fingers each hand down front of chest), three participants (i.e., Susannah, Nora, and Joan) offered additional

signs to connote the intensity of their depressive feelings. An increase in depressive symptoms had its own gesture (i.e., one flat hand pushing down in front of chest). These women also had a sign to indicate severe depression, although the sign was initially interpreted as low self-esteem (i.e., one hand in front of chest, four flat fingers coming toward thumb). The participants stressed that when accompanied by painful facial expressions and exaggeration of the gesture, this sign indicated severe depression.

Several participants reported feeling incapable of communicating the intensity of their depression. When she felt overwhelmed with depressive symptoms, Nora could only say “I want to die.” When Susannah was asked what sign she used to indicate the worst depression of her life, she replied that she had no words but could only say at that time that she wanted to kill herself. Susannah depicted her feeling:

“You don't sign the word depression – you know I, I, it's what I said – I said, I just want to kill myself. My hands just, they weren't allowing me to say it - I was just sobbing so hysterically, I couldn't control it, and – exactly what I said, I just said I will kill myself. That's all I could say at that time.”

Summary of Shared Meaning: Feeling Depressed

Symptoms of depression were described in like words and phrases by the participants. Symptoms included anger, prolonged sadness, crying, low self-esteem, sleep disturbance, appetite changes, fatigue, hopelessness, and loss of interest. Suicidal ideation and intention was divulged by six participants, and several described repeated attempts when feeling overwhelmed by emotion or hopelessness. One sign in ASL was used most commonly to represent *depression*, but was not understood by three of the eight participants. Two participants had no understanding of the finger-spelled word, and these

individuals had a unique sign to represent *depression* that was not known to either the other participants or the interpreters. The next section describes the shared meaning of emotional chaos and life events that preceded the depressive symptoms.

Meaning # 2: How Did I Get Depressed? - Emotional Chaos in My Life

Every participant described challenging life events, extreme emotional hurt and everyday frustration that seemed to precede their depressive symptoms. Their narratives were often accompanied by tears, emphatic hand gestures or ASL signs, and facial grimacing. Stories of intensely painful childhood or adolescent experiences were depicted by every participant, and some described numerous life events. Each participant also reported recent frustrations and situations that felt deeply hurtful. These situations typically evoked feelings of anger, which was observed in their vocalizations, facial expressions, and body language. Two shared concerns emerged (a) feeling different from and isolated from family and hearing or Deaf peers and (b) feeling abandoned by family, friends, interpreters, or co-workers. These shared concerns are further described below.

Emotional Chaos: Feeling Different From and Isolated From Others

Every participant related feeling different for most of his or her life. Most described feeling different even within their family. Eight participants described their childhood as being spent in isolation and all described late adolescence as a time of extreme loneliness. Each narrated their sense of not belonging or feeling a part of any social group or network, including their early encounters with other deaf students. Participants described feeling different in many encounters, including with the hearing members of their family, while playing with hearing children, when first around Deaf

children, when dating, and at work. The sense of not belonging was also connoted by not having access to information, feeling abandoned or left behind, and even by feeling abused.

Living as a deaf person in a hearing world frequently resulted in communication challenges and feeling daily frustrations of deafness. The term *broken* surfaced frequently, as several participants stressed that they are Deaf, not broken. Inevitably, these experiences accentuated the perception of being different from others. The following discussion outlines feeling different and feeling isolated, and begins with early childhood.

Feeling different and isolated from family. Only Eileen recalled feeling included in family events. All other participants chronicled being a witness to rather than a participant in family events or interactions as children. Most shared their longing to be a part of the family and family events and described feeling isolated or set apart from their families. In each case, such experiences were described as hurtful or frustrating and usually associated with anger, self-doubt, and feeling no common understanding. Most participants labeled their family members who never learned to communicate in ASL as not interested or not caring.

When feeling fear, pain, angst, or overwhelmed, deaf children often reached out to their parents for comfort. As depicted by some participants, the family member was unable to meet the needs of the child. When Susannah lost her hearing, she felt afraid and worried about her future; she recalls wanting to be listened to by her mother. Instead, her

mother pushed her and became her speech therapist. Her reaction was to turn inward. She tearfully described:

"Mom just didn't listen to me, didn't listen to my feelings – just pushed. My only safety was in my books, that was my world. I had to drop out of choir – and I loved to sing. My dad stopped calling – he blamed my mom for my deafness – they divorced. I thought, if you won't listen, I'll keep it to myself."

When discussing her father, Susannah reported that he couldn't be bothered to learn sign and emphasized that he still does not know how to sign; consequently she had no relationship with her father after her parents divorced. Brigid tearfully related that she felt left out around her siblings and parents because there was no common means of understanding; she felt lonely and alone until she reached adulthood. Casey's parents do not sign, and attempts at communication have always necessitated simple gestures. He offered depictions of his childhood as lonely, isolated, and not feeling like he belonged within his family. Nora lost her hearing at the age of five, and expressed her feeling of family:

"When I'm with other, like family that don't sign, I feel just horrible, stupid – and it just deflates my self-esteem. Because there's no, I have no way of communicating with them. I can't really have an in-depth conversation with them. Maybe if one-on-one, and we're talking and there's no distraction and it's quiet in the room I might be able to do that some, but it still feels awkward, you know", and "I don't feel that I have the right to force them to communicate with me, because, you know, from my perspective they're not willing to learn sign language, they can't be bothered...to...deal with my problem."

Joan believes that her depression started early and she expressed that she never felt like she belonged in her family; she felt isolated and different from everyone in her

life until she left for Deaf residential school as an adolescent. After her mother's death, she was raised by her grandparents and through tears, she narrated:

“My grandmother and grandfather didn't sign. My father never understood deaf, never understood what it was to be deaf, and he's still alive, doesn't understand me - he's going to be 80, and he still doesn't get it.” He “really just refused to learn sign language to communicate with me he just refused – I don't know exactly why he refused. He's like nothing – he's like a zero to me.”

As deaf children from hearing families, these individuals grew up feeling isolated from their siblings and parents because there was no common means of communication. This resulted in the deaf children feeling different from their families and being left with no sense of belonging. The participants described emotions including resentment toward family members who did not attempt to learn ASL, frustration at not being a part of the family, and feeling let out of family dialogues. One consequence of being different and isolated from other family members was feeling excluded or isolated from important family conversations. This is further described below.

Feeling isolated from important family conversations. As a result of the deafness, most participants had no common means of communication within their family. Stories were depicted in which the deaf child or adolescent was unable to follow the nature of the conversations within the family. Participants related that they could tell by visual cues that family members were discussing important exciting or catastrophic events, but the deaf person was isolated from the actual content of the discussion. This frequently left the participants feeling fear, shame, embarrassment, confusion, and further isolated. In each case, these stories were related with tears and anger; anger was manifested by emphatic hand signs, facial appearance, body language, and raised vocalizations or verbalizations.

Many participants shared their experiences of missing out on essential family information. Susannah witnessed her parents' arguments and frequently felt lost and afraid as she wondered what the arguments were about. Before she lost her hearing Nora would eavesdrop when her parents argued. After the onset of deafness, she was able to witness the same arguments but often felt fear when no longer able to eavesdrop; she assumed the arguments were about her. Nora described her grandmother's recent funeral, expressing her feelings of shame and frustration at missing out on some of the common-sense conversations:

"The funeral, you know I didn't, I couldn't overhear any of the conversations, or what was going on. I didn't know, uh, that my grandmother didn't want the family to wear black, you know, and I, they were all talking about it, but of course I missed that. I don't have access to that information –and so, you know, and so I have people come up to me and say hey, why am I wearing black, I always have to ask – and I just feel so stupid that I have to just keep asking all these questions, you know, because no one lets me know."

With tears and anger, Joan recounted the story of her mother's death. Joan remembers having a vague understanding of her mother's illness, and even visiting her mother in the hospital. Joan was never told nor understood that her mother had died. Joan was sent to live with her mother's parents. Two years later, she finally began to realize that something was wrong. When her teacher asked her fellow students what they did for the weekend, Joan began to wonder about her own family:

"Then later in classroom, um, the teacher asks me, you know, what did you do over the weekend - I got to thinking about, where's my mother, so I asked, um, I asked my grandmother where's my mom, she said, she's in heaven." "I never knew, um, I didn't know that my momma was dead."

Casey also outlined family events and interactions in which he felt isolated and therefore fearful. His parents had divorced when Casey was three. Once he began to attend a residential school for the Deaf in first grade, Casey would often stay with his mother on weekends. His mother later had a boyfriend whom she later married; Casey described the living situation as stressful and frightening. He frequently witnessed interactions which caused him fear, and the interactions were even more frightening because he could never hear what was being said. He shared an experience with much agitation in his body language, signs, and vocalizations:

“During the week I stayed in the dorm, um, and it’s about age 12 and I didn’t understand, you know, why um, my mom was an alcoholic, um, and I just didn’t understand why I couldn’t see my mom, um, she tried to kill herself, she cut herself, and I didn’t understand why, you know, I just, I was scared, I didn’t know why. And that was, you know, very serious when she cut herself she had to go to the hospital, so, um, I got to see that, um, and that, um, she got remarried to my stepfather when I was 12, um, and they would argue, I’d see them argue all the time and I didn’t know why, and you know a lot of drinking and fighting and I’d see that a lot.”

Missing out on essential information caused misunderstanding, hurt, fear, and embarrassment. When there was a sense that no effort was made to ensure understanding, resentment toward other family members was noted. Frustration was often directed inward, as the individuals blamed themselves. As the deaf family member was unable to fully participate or understand, there was a sense of isolation and being different; over time this feeling extended beyond family to friends and peers. The following section describes the feelings of being different from other school children.

Feeling different and isolated from other school children. Stories were depicted in which the deaf child was teased by hearing children, and later teased by Deaf children.

Attending public or oral school also heightened the sense of being different.

Unfortunately, the transition into the Deaf culture frequently perpetuated the feeling of being different, especially if the Deaf child was teased by Deaf peers.

Joan felt different from other children. As a child, she was teased by hearing children, and then after beginning a residential school for the Deaf, was teased by Deaf children. She related that she was extremely angry during adolescence, and described that her mind became evil. She recounted her feelings of being teased as a child:

“The kids would tease me, and the kids you know, it’s very limited communication. I couldn’t hang out with normal hearing kids you know, it’s just very different. And the hearing kids would tease me and would get mad. And then {at the "away" school} I had a hard time accepting the teasing from the {Deaf} kids – I just didn’t get it. I was upset – afraid inside because the kids were just teasing me and couldn’t stop, you know I just stopped talking.”

Experiences with public school education often caused frustration, anger, hurt, and further isolation. Deaf children were often teased by their hearing peers for being different. Supportive services available to the Deaf child were frequently lacking. Speech-reading and oral speech were emphasized, and while several participants described themselves as skilled speakers or lip-readers, universally the participants reported frustration and anger with their public school experiences. Occasionally, an authority figure such as a teacher or parent chastised the Deaf child for not trying, not speaking, or not succeeding. Most participants recalled their public school experiences as painful, and extremely difficult.

Anger and frustration ensued when a Deaf child was labeled as not trying or when trying to meet the expectations of others. Speech-reading and oral speech were stressed,

and the learning process was often challenging and frustrating. Through tears, Susannah related her experience with public school and how it affected her relationship with her mother:

“My mom pushed me, she became my speech therapist – she just pushed me and pushed and said that I will learn to speak. My mom became my speech therapist and stopped being my mom – but I really wanted a mom. That really hurt – mom just didn't listen to me, didn't listen to my feelings – just pushed.”

Even for those who described themselves as skilled at speech-reading, they still felt different than the hearing children. Susannah's experience included being criticized by teachers, her mother, and her doctors, and related being accused of not trying hard enough. Nora believes that people have higher expectations of a Deaf person who is also a good lip-reader. Sean shared his perspective about feeling different at school:

“At school, no one used ASL. My parents wanted me to lip read or use signed English. I worked hard to be like a hearing person but was never accepted.”

Overt manifestations of anger occurred during adolescence and young adulthood, and were frequently precipitated by feeling different in school. Sean recalled first having depressive symptoms during his school years, which he described as a time of intense anger; he related that his grades dropped and he no longer cared. Joan started oral school at the age of four, and continued until what she described as her anger becoming a problem. She related that she was always in trouble, and was sent away to school as an adolescent. She described a class for the hard of hearing:

“I went to a hearing a public school and no interpreter so I...wander around, they were always fighting, and the classroom, it was terrible because the teacher was talking and I didn't understand what she was saying and it was a waste of my time. You know I didn't learn anything.

You know I wanted an education I wanted to learn math I wanted to learn to speak English, and wanted to write and read and you know when they were talking you know it was almost like talking was more important than reading so I just didn't get it and that made me angry.”

The Deaf children were regularly teased by their fellow hearing students but also by other Deaf students. Many participants transferred to an educational system that utilized ASL in the classrooms. Unfortunately, the teasing continued until the Deaf child was able to communicate in ASL. Joan described transitioning from the hearing school where she felt alone and different, to the Deaf residential school, where she continued to feel different; she did not know ASL, thus was teased for being different from other Deaf children. She retreated and stopped trying to communicate. Casey related that his first grade in Deaf residential school was a time of painful teasing, until he learned some sign language.

Universally, the participants narrated stories of feeling left out of events or activities as they interacted with hearing people. When relating their encounters and ensuing feelings, narrations were frequently accompanied by sadness, tears, or anger. Feeling left out of activities exacerbated the sense of loneliness and isolation. As the participants experienced a distancing from others, they were left with a sense of not belonging to the hearing world.

As children or adolescents, the participants often experienced the sense of being left out or separated from others their age. Brigid related feeling ignored by the hearing children, and she did not know any deaf children until she was a young adult. She explained that as a child she constantly felt lonely and alone. Both Brigid and Ciara related feeling lonely, alone, and angry as children. After Susannah lost her hearing at the

age of 13, she felt separated from her hearing friends; she turned inward as her world became smaller and she isolated from others. Joan did not know any other deaf children, and recalls hanging out with some hearing children; she related attempting to get along through gestures, but often was left behind. She described:

"I just got angry you know. I didn't feel like I fit in right, um, you know. My experiences and their experiences really didn't match – mesh – um, you know our communication it wasn't very well and so we talked very little."

As the children entered adolescence, the differences affected dating, which is described next.

Being different and isolated when dating – finding a partner. The nature of relationships may begin to change in adolescence. As related by several participants, the expectation is that hearing adolescents go to parties and dances; several participants expressed sadness at not going out to such gatherings. Watching hearing siblings go out on dates caused some participants to feel different. Some lamented not having a relationship. Brigid recalled really wanting a boyfriend. Sean identified feeling depressed in high school, when he was alone; he felt different from the hearing kids and did not know any Deaf people. He wanted a girlfriend but related that it was hard to meet women because his deafness made him stand out as different. Eileen related feeling frustration as she thought about dating and being different from the other adolescents:

"I couldn't socialize out in the yard with the other students so um, you know, high school's a time for socializing, for experiencing that and learning that – how to meet boys, and that wasn't happening for me at all. I would get real sad sometimes because I was a teenager – I was 15 and 16 and I wanted a boyfriend, I wanted to party and I wanted to do all these activities and keep myself busy, but I couldn't. And boys were kind of scared of me, they didn't know how to communicate with me." "There

was no parties for me, there was no group socializing or anything like that. Sometimes I felt really overwhelmed, you know, like how, how would I go on.”

The difference between hearing and deafness was noted when discussing relationships. Apprehension was pronounced, especially if contemplating whether to date a hearing or Deaf individual. Several participants shared their feelings of dating, when considering the perfect mate. The two male participants had each dated hearing women, and Casey ultimately married a hearing woman. Susannah shared her fear about finding a partner:

“Will I ever meet a man and get married? Will it be a Deaf man? What if it is a hearing man – how will that be? That is really scary – what if it is a hearing man, I love him but he doesn't understand how to live with a Deaf person. Lots of what-if's.”

As a very intelligent woman, Eileen wonders how she will find a match. She has dated hearing men but feels that the differences between Deaf and hearing people are barriers to sustaining a relationship with a hearing partner. With emotion she shared her perspective, and vows that it is better to be single and alone than in a bad relationship:

“A hearing person can never understand my life – they just couldn't, it's not possible. I find a good match, personality, OK, so then we're going along in the beginning it's good, and then the problems start to show up. And the reason why is OK, maybe the hearing person learns sign, yea, and they can communicate, the two of us can communicate fine, but they don't understand my life, my frustrations, like why I'm upset or why I'm sad or why, they don't understand those things. They can't handle it, they just can't. They can't date me, um, they can't have a relationship with a Deaf person, they just can't do it. So it really, it hurts. It hurts inside, right, because then I'm thinking, well what's wrong with me, you know, like what's wrong?”

While dating a hearing person has its difficulties, it is clear that finding a match or another culturally Deaf adult is equally challenging. Differences in life experience and

education are evident. Joan depicted feeling trapped by her Deaf husband, and believes that if he found another partner, she might be free to pursue her own interests. Eileen, Nora, and Susannah worry that their intelligence and education make finding a Deaf match very difficult. As summarized by Eileen:

“For a Deaf woman to find a Deaf educated man, boy that’s tough! There’s not a lot who live in Reno and not in other areas either really, it’s tough, um, and really, a match – to find a good match.”

The experience of dating and looking for a perfect mate is frequently stressful, but for many culturally Deaf adults, this experience is intensified. Differences between hearing and Deaf individuals are pronounced. Communication barriers between partners may be eliminated, but the daily challenges faced by Deaf adults make mutual understanding virtually impossible. It may not be any easier or more likely to find a partner within the culture.

For many participants, the differences between the hearing world and the Deaf world became even more pronounced as they entered adulthood and the work environment. The next section depicts the sense of being different today, as a Deaf adult.

Feeling different and isolated today: participants as Deaf adults. The perception of being treated rudely contributed to the participants’ feeling of being different. Most participants had experienced the sensation of being stared at while signing or communicating. Being stared at caused emotions such as anger, hurt, or embarrassment, and enhanced the feeling of being different. As adults, some experienced being laughed at, or being seen as stupid. Being treated rudely by hearing people accentuated the self-perception of being different.

Many participants described wanting to hide their differences, which included hiding emotions, and even trying to hide the deafness. Susannah acts manic sometimes to hide her sadness. During all three of her interviews, she related with much emotion how she puts on a false front and has to act hearing especially when she is expected to be an example to other Deaf adults. Sean chronicled situations in which he worked hard to be like a hearing person and thought that if he could hide his deafness, people wouldn't stare. Nora hides her anger so that outside everything seems fine; she related that she has hidden herself for so long that she doesn't even know who she is any more. When she feels embarrassed after missing a part of a conversation she makes jokes about being a dumb blonde. She has been working with her counselor about this, as she has spent so much time hiding her deafness and trying to be what she thinks people want her to be. At the age of 12, Joan tried to hide her deafness, and tried to be a good girl; this also meant keeping her anger inside.

Many participants provided illustrations of feeling separated now, from their hearing peers and colleagues. Maire related several experiences from her work environment, in which she felt isolated and left out. Through tears and loud guttural sounds she described her relationship with hearing colleagues:

“Alone, everyday alone. At work I eat alone. Other people get together and meet after work, but they don't ask me to go.”

Maire related that she hates it when hearing people stare and feels angry when people at work ignore her or laugh at her. With anger noted on her face and in her gestures, she proposed that hearing people laugh because they think she is stupid. Sean shared that he gets along with some hearing people but feels that hearing people stare and

then just stop their conversations. Brigid related that sometimes hearing people get mad at her and make faces, and shared an episode where she felt different:

“At the store, I go to buy milk and eggs. I don't know how much one thing cost. I find a person to ask, and when I asked him how much the eggs cost, he walked away. Another person came up and I asked him but he walked away. I went to the front of the store to pay, and I didn't see the cost. I asked for a paper to see how much it cost, and couldn't see the cost. People in line were mad at me, making faces. The lady I tried to pay got mad, and another lady came up to take the money.”

Many participants echoed the sense of being laughed at, and emotional reactions to being laughed at included anger and feeling hurt. Susannah has experienced being laughed at and feeling different, which causes her anger: “If I have to ask about something that seems obvious – I see people roll their eyes at me or their friends, then laugh.” Nora often feels different from the hearing people around her. She shared her perception of hearing peoples’ attitudes toward her and feeling different:

“People, you know, you're deaf, you're, you're broken – you're used goods, you know, and, and you can't have expectations because you're deaf. Most of the time I feel stupid because, you know, I don't understand everything that's going on around me. Because I'm deaf it automatically means, you know, of course I'm different and, and, you know, people look at you differently, and, and, I'm always sensitive about that.”

Joan mentioned that she has tried to make friends with hearing co-workers: “I had a hard time making friends with the hearing coworkers, you know I tried but they kind of, they just perceived me differently.” Eileen’s belief is that there are two personalities: what she labels a hearing personality and a Deaf personality. She contends that one inherent difference between these personalities is hearing values and Deaf values. She also proposed that differences in body language and eye contact contribute to misunderstandings. She described that hearing people often look around the room while

they're talking, whereas a Deaf person must look the speaker in the eye. Furthermore, she related that hearing people have a poker face, and as Deaf people attribute so much meaning to facial expressions, the difference in the use of and interpretation of facial expressions is significant.

Susannah depicted her life as busy, and related that in spite of spending time in the company of friends and her mother, she frequently feels alone. She believes that when she is around people, hearing or Deaf, she is "responsible" for the communication. At times, she "just doesn't feel like" being the facilitator of conversations. At times, she feels alone and lonely even when surrounded by people. She offered one example:

"Living part-time with my mother but still feeling alone, isolated. Or having Deaf or hearing friends around me, especially hearing, but feeling like if I don't work at it, communication, then I just get sort of left alone."

Communication barriers contributed to the sense of isolation and not belonging. Misunderstandings and feeling left out or lost during a conversation often led to emotions of embarrassment, frustration, or anger. Eileen recalled her onset of deafness as leading to low self-esteem, and as a result she began to turn inward and self-isolate. Nora described herself as a very skilled lip-reader, and related that she has as many hearing friends as Deaf friends. Despite her skill at speech-reading, she often feels left out of conversations and frustrated when she misses a key concept. With tears and emotion in her spoken narration, Nora articulated her need to work with an interpreter in order to capture the entire conversation:

"It's just, it's just that, you know, that need to rely on other people, to have a, a conversation, a clear conversation. You know, I can't have a clear conversation without an interpreter – you know, I'm, you know I want to be independent and I want to be able to go out on my own, and I yes I can

lip-read, and yes I can speak – but you know I still, there's still gaps, I have still things that I miss.”

The feeling of being different evolved from observing the actions of hearing people, and by experiencing the reactions from hearing people toward the deaf/Deaf. Inevitably, a discussion of being different led the participants to volunteer a story of how he or she felt limited by their differences. The next section depicts the participants' perceptions of how differences altered event outcomes or limited their opportunities.

Feeling different: barriers to reaching one's goals. Descriptions of events were often followed by speculation on how life might have been different had the individual been like everyone else. Several experiences were related tearfully or with angry vocalizations or gestures. Self-blame was evident in some narrations. Susannah believes that she was responsible for her sibling's traumatic death, and therefore also responsible for her family's sadness; she declared that the death would not have occurred if she had been able to hear. Ciara and Brigid proposed that they would be blamed for sexual abuse by a relative because of their deafness. Casey recounted his mother's suicide and suggested that he could have helped his mom if he had been like all the hearing people in his life.

The effect of divorce on the child or the family was often discussed. Five participants lived through their parents' divorce, and all felt responsible for the divorce. Susannah worried that she was blamed for the divorce, especially by her father; once he moved away from the family, he stopped seeing her. She related that she was responsible because her difference as a deaf person caused stress within the family.

Some offered what they might have been able to achieve without deafness. Going to school, going to a good school or going to college was mentioned. Sean and Casey used the sign *smart* when describing themselves, and each related that they would have gone to school or university if not for their deafness. Joan believed that she could have gotten the education she wanted if not for her deafness. Several lamented needing an interpreter to have any meaningful conversation, and this difference led to feelings of anger and frustration. With much emotion in her voice, Eileen verbalized her perception of what she “lost” when she became deaf:

“Every day, every day little things like I can’t go watch a movie – I just can’t go out any time I want and watch a movie. You can call people any time you want, you have a cell phone, you can just call, it doesn’t matter, you can just talk at will, any time you want. But I can’t. So, when I’m driving, sometimes I’m on a long drive, what am I doing? You can listen to the radio, you can hear music, for me, it’s boring, I’m just driving. You know, it’s little things like that. It’s frustrating.”

Being blamed and being responsible were commonly reported. Several identified what they might have been able to accomplish if not for deafness or if they had been like hearing people. Many also identified their inability to reach their dream.

Everyone shared at least one aspiration that had not been attained. Some reasons for not fulfilling a dream included having lost opportunities, or being prevented because of deafness. After losing her hearing in adolescence, Susannah had to give up her choir which she loved and her dream of being a ballet dancer. Eileen’s aspiration was to obtain her Masters in Business Administration (MBA); after losing her hearing she decided that she would be too different from hearing people, and changed her major to English Literature.

Several believe that they were prevented from reaching their dream because of someone else's perception of the differences. Inevitably, these stories were related with anger in voice, facial expressions, or hand gestures. As an adult Susannah's dream was to work in health care. She reported that she had a 3.8 grade point average, but was denied admission to a program and felt disillusioned and hurt. Susannah and Sean wanted to attend a particular university but were prohibited by their parents. Maire's dream is to have a baby but her mother forbids it. Nora suggested that Deaf people are limited because hearing people see us as broken. Sean's dream was to be a river guide, and shared his experience:

"I wanted to be a river guide. It wasn't possible. No company would hire me. I talked to one company. They said I couldn't hear people shout for help. I'm good – it was possible! I wanted to guide. There was no respect for my skill as a kayaker. I was really pissed off! It wasn't right. It wasn't fair. I'm good – I was good. I was a strong kayaker. I had already helped people stranded on the river."

For many, feeling different was associated with feeling disappointment. Some described feeling like they had failed. Others felt like they could have or should have been able to accomplish their dream if they had not been limited by others. Many blamed their not fulfilling a dream on the differences between hearing and Deaf people; these differences were associated with lack of understanding and differences in expectations. Most participants described these differences but also related the necessity of working through and negotiating the differences; this is discussed next.

Feeling different and isolated: negotiating the differences. As Deaf adults navigate the hearing world, there are potential moments of angst, frustration, fear, anger, and resentment. Many participants conveyed their enjoyment of some hearing people. All

emphasized the difference between living in the hearing world and the deaf world and it was frequently expressed that hearing people could never fully understand living with deafness. Even for those who feel confident navigating the hearing world, negotiating through both worlds continues to be challenging. Stories were recounted of prejudice, cruelty, and aggravation, and typically portrayed with much emotion.

Several differences in attributes were noted. Hearing people were identified as being impatient and controlling, and Deaf people in general were noted to be nosy. Negotiating both worlds was sometimes made more difficult when the participant had lived in both worlds. Eileen explained a difference between her hearing friends and Deaf friends: "The hearing are more flattery, they beat around the bush and find a nice way to say it", whereas her Deaf friends "are really straight forward – blunt – they will just blurt it out." She expressed her discomfort with her Deaf friends she sees as "really a little bit nosy", and related this to the small size of the Deaf community: "they feel more like a family and so they want to know everything about each other – everything!" She also discussed some frustration with impatient hearing people but also says she continually learns to lean on hearing people.

Negotiating the difference extended to friendships. For some participants, having hearing friends actually strained their relationships with Deaf friends. For others, the perceived differences in behaviors and attributes between hearing and Deaf caused confusion or discomfort. Susannah conveyed that most of her friends are hearing because she relates better intellectually to hearing people, and her Deaf friends feel she sets the bar too high.

Hearing friendships also caused frustration and stress, especially if the friends were not fluent in ASL. Several participants described feeling the need to broker conversations. Susannah related her discomfort with communication around her hearing friends who do not sign; this leaves her feeling responsible for all the communication. Eileen identified that even though most of her hearing friends have learned to sign, the differences between Deaf and hearing can affect the friendship:

“All the way through, there’s frustration with life, trying to function in a hearing world, um, trying to relate our experiences, some of them can’t understand my life – they can accept it but I’m more comfortable with people who have a deep understanding about what it means to be deaf.”

Forming friendships and associations with hearing people who do not sign fluently can accentuate the difference. Most participants conveyed that they had hearing friends and all tended to prefer friendships in which the hearing person learned to sign. Every participant related that the quality of the signing was less important than the fact that a friend tried to sign. Several described situations in which they balanced the desire for friendship with the stress associated with being the interpreter. Eileen reacts to socializing with hearing people who do not sign:

“A hearing person is mostly their family, their friends are mostly hearing too, right, so what happens is when the two of us go in to a family function or something, the family group all get together and what happens, they need to interpret for me, and then that’s a lot of responsibility – how can they really enjoy themselves and make sure that I enjoy myself too and then be an interpreter at the same time, it’s really tough.”

Communication barriers and misunderstandings often led to decreased self-esteem. Inevitably, being different from other family members or peers, and differences in communication became painful experiences. These experiences incited emotional

responses such as fear, anger, sadness, resentment, low self-esteem, embarrassment, and shame. The numerous experiences also reinforced the differences between the deaf individual and the hearing world, and promoted the perception of not being normal. In some cases, the participants also felt an extreme sense of abandonment; this inevitably exacerbated the sense of being different and feeling isolated. The concept of abandonment is further described next.

Emotional Chaos: Feeling Abandoned or Abused

Each participant shared stories that depicted their sense of abandonment. Most participants described feeling abandoned by parents and/or sibling. Eight imparted feeling abandoned by hearing peers, and each felt subsequently abandoned by deaf/Deaf peers as they transitioned into the Deaf culture. Several elucidated feeling abandoned by someone significant in his or her life, such as an interpreter.

Several participants depicted feeling distance from or abandoned by a sibling. Eileen related feeling very supportive by her family, but then emphasized that she did not feel close to her sibling; she surmised that her sibling was jealous of the attention directed toward Eileen after her hearing loss. She and her sibling grew apart, and now have no contact with each other. When Maire was asked to describe a time she felt an extended sadness, she tearfully recounted feeling that her sister had left her behind:

“When I was a child, my sister and I were happy, we laughed – then my sister went to school, left me alone – then I was sad, angry.” Maire declared her intent to ensure that she is never left alone again: “Deaf babies. I would be happy – I love babies and I want deaf babies; Deaf husband, deaf babies and children, I would never be alone.”

Although Susannah sometimes feels frustrated at needing an interpreter, she also views her interpreter as a link or lifeline to the hearing world. She recently experienced a sense of abandonment with her sign language interpreter. She described this as a stressful and hurtful experience, and believes that it precipitated a period of depression. She related this event with tears and in a raised voice:

“Classes I was taking were stressful. One class really hard, three weeks after starting, the interpreter just quit – left. I had the same thoughts over and over, even when I tried to sleep. Some things I was able to push away but others like the sadness and...some things just made me angry and I couldn't push them away.”

Ciara portrayed her married life as happy, especially when her two Deaf daughters lived at home. She experienced a feeling of abandonment when her daughters left for college. She described feeling mixed emotions when her daughters left; while she felt proud of them and excited for their future, she also felt lonely and alone. Ciara was asked to relate a time when she did not feel sad:

"When my daughters were home and I was married. I wasn't alone – I wasn't lonely. He signed, my daughters signed."

After Joan's mother died from complications related to diabetes, Joan was sent by her father to live with her grandparents. She recalls relatives coming by the house and crying, and then having her father and grandparents leave her home alone with a sitter. She became quite tearful as she related this sense of abandonment:

“I remember my aunt, my aunts and uncle that night, my grandmother and grandfather and my father flew – I remember that very clearly – but I had no idea. They're not there, and I, you know I arrived at the place where my mother's grave was, and they left me with the babysitter while they all went to the funeral. I was in, I wasn't there for the funeral. I just, I had no idea.”

Casey had no siblings. He had no contact with other young children until he went to Deaf residential school at the age of six. He was sent periodically to live with his grandparents. With much emotion in his face and signed gestures, he related his first experience being sent away to school:

“You know, it was terrifying. You know, my mother just kind of threw me in the room. And I remember that I cried and, and or, and my mom didn't cry – she didn't cry. Um and I remember the teacher kind of helped me to calm down – I was so upset and you know, felt lost, you know, where's my mother ? I didn't understand, I didn't know why, why I was just kind of left there. Um you know I didn't know where my mother and father were – they were gone. You know, and that was terrifying.”

For some, being physically, emotionally, or sexually abused felt like being abandoned. Several participants described witnessing physical or emotional abuse, and three related feeling personally attacked physically or emotionally. Three women also reported being sexually abused by a family member or relative. Susannah and Nora each described their relationship with their father as abusive. Nora related that her father was always emotionally abusive, calling her names, ridiculing her for her deafness, and telling her she was a failure. She narrated:

"I joke about it to cover it up, um, I tend to hide my concerns, but you have to understand, I always feel that, that I'm always having to prove myself to him, you know I'm always wondering like what's wrong, do – are you stupid, or...do I not look good enough, or you know, I'm just paranoid."

Susannah provided examples of her father's angry and abusive reaction to her assimilation into the Deaf culture. When Susannah was expressing her feelings about her frustrations and difficulties related to deafness, she began to describe her father as:

“He was abusive emotionally, verbally, physically – and it got so much worse after I lost my hearing. My mom ran off with someone – he blamed

me for the stress and her leaving. I just became so much more visible, a source of stress. My sisters live with my step mom and dad – in order to see my sisters, I had to see my dad – but my deafness just reminds me of stress.”

Ciara tearfully related being sexually abused as a child, by her brother. She related that she didn't tell anyone, because she didn't know who to tell. She did consider that suicide might be easy. With much emotion, she tearfully communicated:

"I have brother, but he is bad – he hurt me in a bad place. He is bad. He hurt me. He hurt me in a place he can't touch – he is not suppose to touch."

Brigid related being sexually abused by her cousin at the age of 14. She did not tell anyone because she feared being in trouble. As she discussed the event, she hung her head and avoided eye contact. She tearfully reported that:

"When I was 14 I think, my older cousin, he touched my private parts – down there – until it hurt. I didn't tell... because I am deaf – because sometimes people think I am stupid – I can't explain.”

When Joan was outlining her childhood years with her grandparents, she described one period of time as having another crisis, when her father touched her in an inappropriate way. Soon after this crisis she believes that her mind became evil, and she wanted to go to jail. During the second interview, Joan divulged that her father touched her inappropriately several times, stressed again that her mind became evil. She reacted in anger and pushed her father away. While avoiding eye contact, she elaborated:

"Let's see, later, about 11 or 12, we had another crisis – confused, confusing. Because my father touched me – maybe, right before my periods started before, I don't remember how long, maybe two, three years prior, and at age 11 you know, I was wondering why!"

Casey recounted several episodes of physical or emotional abuse from his mother. Frequently when he came home for the weekend, he witnessed his mother hitting his

step-father. In the midst of describing his weekends with his mother, Casey added that his mother tried to kill him. This was signed so subtly that it was almost missed by the researcher and the interpreter, and Casey was asked to repeat the story:

“As I was getting up, um, she tried to, to, stab me, and, was, I’m like, well why are you, you know, I’m scared. Why are you trying to kill me?” “I went out and I went to my stepfather’s store and I you know, said, you know, that my mom tried to kill me and, so I went back home and, and I was scared – you know, I was afraid – I was 17. So, and I was afraid to talk to the police.”

Several participants portrayed their childhood as living in fear of physical harm. Some related feeling lost or confused as to where to find safety or even to know who is safe. When Susannah was physically abused by her father, she did not know where to turn, and believes that it is never clear to a Deaf person who to turn to for help. After Casey’s mother tried to kill him, he was afraid to talk to the police; his search for safety led him to move in with his aunt. When his mother subsequently moved in to the same house, Casey asked his boss for a place to stay. After the crisis in which her father touched her, Joan thought that jail would be a safe place.

Summary of Shared Meaning: Emotional Chaos

Every participant related their sense of being different and not belonging. Eight individuals felt isolated at a very early age, from their families and from their young peers. Feeling left out of important conversations and family events caused fear, anger, and for some, the sense of abandonment. Several felt pushed away by events or acts of abuse. All described adolescence as a time of pain and loneliness, and several believe that their depressive symptoms first began during this developmental period of time.

The sense of self as different was conceptualized early, as these deaf children interacted with their family and with hearing children. Most developed a sense as children that they were different. Experiences in public school left the children feeling deaf-broken or deaf-different. The differences became more pronounced as the deaf children entered adolescence. Events, parties, dating, and dances accentuated the differences as the deaf individual was again left behind. The differences continue to be experienced through interactions with hearing individuals. Negotiating the hearing world is often fraught with frustration, and as described by each participant, often necessitates reaching out to others. The next section outlines the shared meaning of reaching out to others in the hopes of being heard and understood.

Meaning # 3: Reaching Out

As deaf children and Deaf adults, negotiating the hearing world may necessitate reaching out in the hopes of being heard and understood. Stories were shared of reaching out for understanding when feeling emotional pain, and these were typically depicted through tears and expressions of sadness. Some recounted their attempts to reach out for safety. The future was brought up during most interviews, and emotions ranged from fearful to excitement. Two shared concerns surfaced: (a) reaching out to others and (b) reaching for the future. The participants' efforts at reaching out to others are discussed below.

Reaching out to Others: Wanting to be Heard and Understood

Every participant related one or more experiences of reaching out to a hearing person or agency. Some experiences were described as very positive, while others caused

pain, embarrassment, disappointment, or shame. Relationships with interpreters were described, sometimes with resentment but often with gratitude and respect. When chronicling frustrations, the topic inevitably turned to health care; stories were related in which the Deaf adult was embarrassed or ashamed in the health care setting. Several adults outlined their efforts to obtain a diagnosis or seek mental health care.

Interpreters. Several stories involved a situation with an interpreter. Most described the role of interpreter as being a valuable link to the hearing world, and when concerns or conflict arose between the participant and the interpreter, emotions such as frustration and anger were felt. Some participants recounted a humorous interaction with an interpreter, and several described frustrations and difficulties with interpreters. Concerns about interpreter confidentiality was identified by some participants, and in each case, anger was expressed. Other concerns included lack of skill, lack of availability, being a friend and difficulty having schedules match.

Having interpreters in mental health care settings was controversial. Every participant who had sought mental health care expressed their reluctance or even disdain at being with an interpreter in this setting. When he was thinking of suicide Sean considered reaching out for help; he did not want to take an interpreter because he didn't want anyone to know. Susannah has been seeing a counselor for her depression but has never wanted an interpreter present because she is embarrassed to have her interpreter know about her suicidal thoughts, depression, and suicide attempts. She has had several interpreters who violated confidentiality; therefore she has a hard time trusting and feels the community is too small. After attempting suicide, she worried that her interpreter who

is a personal family friend would find out about her attempt. This caused her to feel very anxious and ashamed. She has worked with interpreters who only knew the alphabet, and sums up her perspective:

“It makes it hard! So I would rather ignore my depression than work with an interpreter who can't or won't sign or who breaches confidentiality.”

When seeking health care, interpreters were usually desired. However, most participants recounted stories in which the interpreter was not allowed or discouraged.

Susannah tearfully elected to voice two health care experiences, and orated with anger:

“My first pelvic exam, saw an OB-G, I asked for an interpreter, he didn't have one, so here is my first ever pelvic and he's doing things down there and I don't know what is happening. And I saw a dermatologist who looked at my butt and I didn't understand why – I am having to fight for my rights – and honestly I am just tired of fighting and am really depressed – I just can't fight everyone's fight for them.”

Health care. Most participants recalled being evaluated for deafness. Stories of examinations, needles, x-rays, and doctor visits were recounted with anger and tears. Occasionally, providers or parents seemed not to believe the child was really deaf. Many portrayed providers as being impatient. Sean believes that it is hard to meet a doctor, especially as some get impatient with him; his reaction is to withdraw and not communicate. When Eileen lost her hearing, she endured numerous tests as the doctors tried to ascertain the etiology of her deafness. She believes that her doctors lied to her about her hearing loss, when they promised every day that she would regain her hearing. Susannah described going for many hearing tests and having people act impatient toward her:

“I'd be like, I can't hear, and finally someone said "she's deaf" {throws up her hands} – and that's what I've been telling you! I felt so lonely – so

alone. The doctor one time turned to my mom and said, "make her answer". My mom said "she's DEAF!"

Once diagnosed or assessed as deaf, treatment was often begun. Sometimes the deaf child had an easier time accepting the deafness than did the parents or providers. Susannah recalls knowing that she was deaf and wanted to learn ASL, but her mother and providers kept looking for the etiology of the deafness. For her, the experience of being diagnosed was a source of frustration, anger, and hurt. Joan's reflection is that her mother was compulsive and put all her energy into finding treatment, going from one specialist to another. Eileen believes that the effort at diagnosis and treatment leaves children feeling broken, and with anger on her face and in her gestures related:

"The medical perspective is very different about deafness – a lot of deaf kids grow up with that medical, that pathological perspective you know, mom and dad don't understand, so the kids, they hear they're broken, we're going to give you a cochlear implant, we're going to give you a hearing aide, we're going to make you hearing – why?"

Health care terminology and communication barriers made understanding difficult. Speech-reading was often expected by providers, but even those who identified themselves as skilled were unable to follow much of the conversation. Several volunteered that when they attempted to communicate by writing, the provider was not willing to do the same. Susannah described feeling stupid for even having to ask when she anticipates that she should know the answer about her health. Ciara has been seeking help for her physical pain, and although she has had tests recently, she related that her doctor doesn't talk to her and she does not understand what he says or what the nurse says. She considers it hard for a Deaf person to ask for help and often feels that her

doctor is angry with her. She depicted an event in which she felt angry with the health care office staff:

“I always tell the lady I am deaf, and one time I sat and sat, and she called my name. I waited and waited...other people in the room went back and I sat, didn't know she called my name. I asked the lady why I hadn't gone to see the doctor and she said they called my name but I wasn't there. I didn't even get to see the doctor and left. I was very angry. I went to a different doctor.”

Several participants described their frustration as patients with the lack of understanding. Stories surfaced about being the patient and feeling that office staff or providers could not be bothered to communicate in a way that ensured understanding. When Casey was describing one frustrating health care interaction, his ASL signs and gestures became quite animated and difficult for the researcher and interpreter to understand. He was asked to repeat several phrases three times; rather than react to the researcher or interpreter with impatience he apologized for his "talking too fast" and thanked the researcher and interpreter for trying to understand his story. As Eileen was describing her feelings of frustration, she turned the discussion to her health care, relating:

“I'm frustrated, um, through everyday life. All the little things, like I can't go to the doctor when I want, and have, because I can't communicate with the doctor. Often hearing people think that they can voice and that I'll understand them but, come on, I don't.” So I go to the doctor, it means I want to know everything about my health, and that's important – I don't want to understand just 60% or 70% or 80% – I want to know 100% but my experience with doctors is they don't want to write notes, um, maybe they'll start and then they'll give up, they'll just want to talk. And that's really frustrating for me.”

Obtaining a prescription refill was often a source of frustration. Several participants recounted struggles to find someone or get help. With anger observed on face

and in gestures, Susannah, Nora, and Eileen described efforts to make a doctor's appointment or refill a prescription. Eileen then wondered what might happen in an emergency. She related her frustration:

“People they don't understand how to use the relay, the relay person and how that goes and they just hang up on me and so I have to call again and again and again and again and say please, and explain, and then the relay operator that I use can be really slow, which means that sometimes on the phone, I'll be on the phone for 50 minutes doing something I could have finished in two minutes, just trying to explain to the person. I can become very frustrated.”

Sometimes, physical assessments seemed to take priority over evaluation of mental status, which often left the child feeling frustrated and hurt. No participant recalls ever being asked about symptoms of depression. Even when seeking relief of depressive symptoms, several related that the focus of the visit became the etiology of deafness rather than the concerns of the patient. Sean related that he would like to talk to someone about his emotions and thoughts of suicide but since no one asked, he didn't talk about emotions. He considered reaching out for help but divulged that there was no one. When asked to elaborate, he explained that no one signs. Susannah remembers feeling more and more depressed but no one ever asked about depression and no one listened:

“I had suicidal thoughts, I remember driving up the mountain road thinking, just drive off the edge. What made me so mad is that the doctors all focused on my physical, what is wrong, why am I deaf? When I tried to tell them, everyone just talked about my physical – that was important to the doctors and my mom and so I just kept the other to myself and withdrew into my books. I think back, people should have talked more to me.”

Several individuals divulged that they are under treatment for depression. No one is working with a provider who communicates in ASL. Joan is the only participant who

has ever encountered a provider who signs, and she identified this provider as excellent. She was first sent to a therapist when she was 15. She felt like she had a black cloud in her mind. She did not find therapy helpful at that time, expressing:

“I went there to a therapist and it didn’t help. Because the psychologist, you know, his signing was mediocre at best. And there was no relationship or bond there, and I just kept quiet.”

She subsequently saw several other therapists. She remembers another doctor who did sign, but she described him as very limited in his ability. At the age of 40, Joan met a psychologist and psychiatrist who diagnosed her with depression and anxiety. The psychologist she saw at that time knew ASL and she enthusiastically related that he was great. She has not seen a psychologist since moving to Reno, and wants to find one who has just a little bit of sign language background and an understanding of Deaf culture. She expressed:

"Um, it’s hard, I’ve moved here, I haven’t seen a psychiatrist since I’ve moved here, uh, I might have to look for one that would understand the culture and language that would maybe have, you know, a little bit of sign language background."

Reaching out for health care and to health care providers left most feeling frustrated. For some, health care experiences were remembered as painful or humiliating. Childhood health care episodes were frequently described as frightening and physically painful, and relating these experiences often prompted stories of childhood. As adults, most frustrations and difficulties in the health care setting arise primarily because of communication barriers. Inevitably, a discussion of the past led to projections about the future. The next section describes the participants' thoughts toward the future.

Reaching Out: Reaching Into the Future

Some described their future with excitement and enthusiasm, connoted by smiles, laughter, and animated gestures. For others, the future seems to be associated with fear and anxiety, as evidenced by heads dropping, slumped posture, shrugged shoulders, and tears. Fear for the future included worries about money and work. Maire shared her fear of no money and wondered how she would care for herself. During two interviews with Ciara she expressed fear about the future because her place of employment may close; she worries about getting a job, money and being alone. Susannah worries about money and finding the right job, which she believes is harder for a Deaf person. Nora expressed fear about the future because she hates uncertainty and because she does not know how to take care of herself financially. Her fear is also based on her past:

“I am frightened of the future, what'll happen, scared of, what's happened in the past, how it will affect my future, it's just a gut, like in your stomach, just that feeling of.....uh...uh, gosh, it's like um, just feeling that everything I want, and that everything I want to do that I can't.”

When thinking about the future, some feared a threat to an important relationship. Frequently, the discussion of fear turned to being alone or left behind. Susannah worried about her mother dying, and wondered how she might be able to take care of herself; she was quick to counter with living one day at a time. Maire fears being left alone in the future, and worries that her Deaf boyfriend will leave. Conversely, Joan fears that she will have to leave her husband in the future, in order to pursue her goal of independence. Several articulated fear of friends leaving the area. Eileen worries that more Deaf people will leave the community in the future, as she described the dearth of supportive services or opportunities for Deaf people in the community. Susannah, Nora, Joan, and Casey

echoed this fear and the frustration with the lack of support and opportunities for the future.

Fear associated with change was expressed. Although Sean now feels content he has felt no hope for the future, feeling that nothing would change. Nora's fear of the future is based on part on her feelings toward the past and her feeling different as she continues therapy. She related:

“You know, really, I'm deeply afraid of the future – because if I ever feel better, I'm.....really, I'm afraid to feel better, because I've been depressed for such a long time, I'm just used to being that way...I don't know how to be happy – I'm the, I'm feel afraid to be happy, cause I really don't know what it feels like to be happy. I think sometimes to be specific, um, you know because it's been going on for so long – it becomes, uh, normal, you just get kind of used to it, and the idea of change is terrifying.”

The future is frightening for some, and exciting for others. When fear of the future was disclosed, it was typically related to money, relationships, or change. Those who expressed enthusiasm for the future also identified that membership in the Deaf culture was the key to feeling a positive sense of future rather than feeling different or broken. The next section depicts the shared meaning of membership in the Deaf culture.

Meaning # 4: I am Deaf – I am not Broken!

Universally, outlining painful, frustrating, or frightening experiences led to descriptions of finding oneself beyond the hearing world. For every participant, learning ASL enabled them to feel accepted into the Deaf culture. All embraced the Deaf culture, which provided a new sense of belonging. However, outward manifestations of the different culture such as communicating in ASL often caused discomfort to others.

Two shared concerns were noted (a) feeling proud to be a member of the Deaf culture and (b) promoting the Deaf culture.

I am Deaf and I am Proud

The definition of Deaf culture was frequently associated with an emphasis of Deaf, not broken. Other distinctions included Deaf, not stupid and Deaf, not disabled. Several stressed that they were not disabled and not hearing impaired. Susannah used the term Deaf – not broken – during every interview as she described herself as a culturally Deaf adult. Nora emphasized that she never felt broken or stupid around other Deaf people as she did around hearing people. Eileen imparted that although hearing was broken, she is still a good person; Eileen also declared that disability is the wrong term for her, as she is not broken but merely different. One of the few times Eileen manifested anger in her voice and face was when describing how she can quickly feel broken around hearing men:

“The person was willing to accept that I’m Deaf, and that’s happened often, the hearing man is interested, yea, and they keep telling me oh, you’re beautiful, you’re smart, you’re so good, and I’m fine and I’m perfect and great, yea, but then they’re awkward you know, so we’re going along and then they get out of it really fast. All these things but then they just, they just run off, you know? It’s wrong. Because inside, inside my self-esteem really takes a hit, you know – what’s wrong with me?”

For those who lost hearing at a later age, there was a need to prove something. Several discussed the need to prove to their family that they were the same person as before the hearing loss. Efforts were expressed as proving that I was equal or even the same person since the hearing loss, and in each case, the stories were recanted with pride noted in face and body language. Eileen imparted her experience:

“I was trying to prove that I was not broken – that I couldn’t hear any more but it didn’t mean that I was different – I wanted to prove that I could succeed, that I, that I wasn’t a bad person, that I wasn’t a broken person, that I was fine. So I always wanted to compete – and there was a lot of stress on me, always trying to prove that I was equal to the other people.”

All reported that they were more likely to feel impaired or disabled around hearing people. The participants stressed that they did not feel stupid, broken, or disabled around other Deaf adults. Feeling impaired or disabled was frequently associated with communicating in a different way through the visual language of ASL.

Members of the Deaf culture communicate in ASL. Many participants discussed their use of ASL and the effect it had on those around them. For some, even the request to learn ASL was a source of friction within the family, but for the participants themselves, learning ASL was a source of pride. Others felt defiant when they took the initiative to learn ASL. Three participants taught themselves the alphabet from a book. As adults, several experienced anger and resentment when a hearing person asked them to stop signing. Susannah recalled asking to sign after losing her hearing, and was angry when her mother and physicians discouraged this. She related that she has felt robbed of her identity and pride when she was not allowed to sign in college. Joan related learning ASL quickly after teaching herself the alphabet from a book. She described several work supervisors; her first supervisor signed beautifully, and this helped Joan to enjoy her work. Her second supervisor could sign a bit, and Joan related that the job was then OK. Her third supervisor threatened Joan's sense of pride:

“I hated her! Bad vibes between us – she was hoping that I would go take a lip reading and learn, improve my English, and that was just impossible for me. Um, so it was frustrating.”

While the Deaf individuals expressed feeling proud of their culture and their fluent communication in ASL, they were often conflicted by close relationships with hearing people. While the Deaf adult preferred to communicate in the natural and visual language, some hearing people related their feelings of embarrassment or discomfort at being with a Deaf person who signed. Relationships became strained with family or friends who did not learn to sign. Many participants described relationships as hurtful if the hearing person did not learn to sign. This also created resentment, and in some cases precipitated minimal or even total loss of contact. Casey's four children never learned to sign, and there has been no contact in years. Joan's father never learned to sign, and she resents this; although he lives in the same town, they have no contact whatsoever. Susannah's father did not learn to sign, and she only sees her father when her sister is visiting. She reported with anger and resentment that her father gets irate when she signs in public. Nora has minimal contact with her father, who she described as having no interest in learning to sign.

The use of ASL often caused disagreement within a family. Experiencing another person's embarrassment when the Deaf individual signed in public left the participant feeling hurt and frustrated. The dearth of family members who sign is still a source of pain for those interviewed. Not learning was usually interpreted as "could not be bothered." For many participants, this caused a distancing of relationships. Membership in the Deaf culture often brought a sense of belonging and feeling whole for the first time but risked relationships with hearing people.

A sense of belonging. During every interview, the topic of *belonging* was discussed. Universally, the sense of belonging was associated with the Deaf culture. Some participants conveyed that the first time they felt a sense of belonging was after meeting their partner, another culturally Deaf adult. The sense of belonging was also associated with improved self-esteem and feeling a part of something. As Eileen became fluent in ASL she felt more comfortable around culturally Deaf adults and felt like she did not need the hearing world any more. Brigid feels happy now with her Deaf husband, and as an active member of her Deaf community. Sean's whole life changed for the better when he met his Deaf wife, and they socialize with other Deaf couples. When Nora was asked to describe a time she remembers feeling happy, she identified:

"When I got to see Deaf out in the community – it was the first time I didn't feel Deaf – broken, Deaf – less, and felt like a Deaf person."

Joan struggles with depression today but is excited with her new business because she gets to meet new Deaf people. With pride showing on her face, Eileen related feeling a part of the Deaf culture:

"I became more involved with the Deaf culture. Um, why, well I knew sign language and so I felt more comfortable in my new culture and my new deafness and my deaf personality – I was a hearing person that couldn't hear any more. I became proud of my deafness and my culture. And my self-esteem – it's good!"

Relationships were frequently reported as important and sustainable when the hearing person could communicate in ASL. Some family members did learn ASL. This was always reported with a smile and a sense of pride was noted. Although Joan's father never learned to sign, her grandmother learned ASL and she related that this enabled them to have a great relationship. She also related that her only positive experience with a

mental health provider was with the one who could sign, and her favorite supervisor at work was the woman who signed perfectly. Casey's mother and stepfather never learned ASL. He described his father as wonderful – and his father learned to sign. Eileen, Susannah, and Nora each conveyed that they are more comfortable with hearing friends who can sign. Brigid depicted her life as much happier now with her Deaf husband and her hearing kids who all sign.

The sense of belonging improved self-esteem. As self-esteem improved, some participants were able to laugh at themselves or certain situations. Nora recounted being a bridesmaid in a friend's wedding and having to wear white tennis shoes with dark blue formal dress because she had an air cast on her ankle; with laughter she described the nick-name given to her by her friends – “White girl can't dance”. Joan laughingly depicted sitting in the oral classroom and having to listen to headphones, then turning the headphones off and still being able to answer the teacher's questions. With laughter and smiles, every participant shared at least one humorous story.

When Ciara feels lonely and misses her children, she communicates by e-mail. With very animated gestures and a huge smile, Nora described her new fancy version webcam which enables her to talk to friends; she expressed that this is so much better than the old TTY. Joan feels lonely and frightened now, and hopes that she can meet some new Deaf people on the internet and on the web. While Eileen experiences frustration daily as a Deaf person, she loves technology and the ability to connect with her parents:

“My parents try and talk every day with me and technology is wonderful! Um, we use the webcam and we use the internet and we chat on IM and I try to contact them every day.”

Today’s technology has made it possible for Deaf adults to stay connected. Most participants shared stories that illustrated how technology helped them navigate the hearing world while also enabling them to connect with others. In each case, these stories were related with smiles and enthusiasm. As some of the participants experienced a strong sense of pride associated with their Deaf culture, they thought of sharing their knowledge and experience with others. The final section depicts some participants' efforts to promote the culture they embrace.

I am Deaf and I am Promoting my Culture

Forming relationships with other culturally Deaf adults enhanced the sense of belonging. Many expressed their desire to also sustain relationships with hearing people who understand the culture. Some participants desired to help deaf people become a part of the Deaf culture. Four began to teach hearing people about the culture, wanting more hearing people to understand Deaf not broken. Susannah, Joan, Nora, and Eileen teach ASL courses. These individuals also tutor other deaf people who are in the process of learning ASL. Joan asked the researcher to let people know how isolating public school can be, so that other deaf children don’t have to go through what she did. Susannah and Nora teach Deaf culture courses. Eileen sees herself as a bridge between the Deaf world and the hearing world. She asserted that her life goal now is to teach hearing people so that they understand what it means to be deaf and to help other deaf people see that they are not broken. With much passion in her face and gestures, she imparted:

“A lot of deaf kids grow up with that medical, that pathological perspective – mom and dad can’t sign, so the kids grow up very isolated always underneath this hearing perspective and that’s all they have, so that’s all they have to compare themselves to, other hearing people, and when you’re making that comparison, you know you’re different – you can learn to communicate, you can learn things, you can socialize, you can talk about what’s wrong and what’s right, but most of them have no idea – the environment influences them – that’s the message they’re brought with, that’s what they hear. But being deaf is, it’s very different – the perspective is very different. So I’m deaf, so what! So what – nothing’s wrong. I can communicate well – I can function well – OK I’m different, yea. It can be accepted as different.”

Summary of Shared Meaning: I Am Deaf

Every participant self-identified as comfortable with and embedded in the Deaf culture, but they were not insulated from frustrations and challenging experiences. While the culture did not insulate these participants from experiencing symptoms of depression, membership did ameliorate the symptoms of low self-esteem and isolation. Although enculturation was essentially positive for the participants, it often had a negative effect on some significant relationships. The relationships described as positive, helpful, and enjoyable are with individuals able to communicate in ASL. The concept of understanding is so important that some participants have chosen to teach cultural sensitivity courses and ASL to hearing people.

Summary

Chapter IV presented an overview of shared concerns and descriptions of shared meanings. Individual concerns, shared concerns, and abstractions of shared meanings were identified and illustrations were provided to support these abstractions. For all participants, experiences in childhood triggered feelings of low self-esteem, abandonment, isolation, and self-doubt. Most continue to experience episodes of

isolation, frustration, and pain while navigating the hearing world. These experiences undoubtedly increase the risk of depression. Membership in the Deaf culture cannot completely shelter these individuals from pain and frustration, but may contribute significantly to improved self-esteem and overall morale. Chapter V will provide a discussion of these findings and convey the study implications in health care.

CHAPTER V: DISCUSSION AND CONCLUSION

The final chapter elaborates on the concerns and meanings that were shared by these culturally Deaf adult participants as they described their symptoms of depression and discusses findings in relation to the literature. Four abstractions of meaning emerged during data analysis: (1) feeling depressed; (2) emotional chaos leading to depressive symptoms; (3) reaching out; and (4) feeling proud to be a member of the Deaf culture, are discussed in relation to the literature. The researcher's pre-conceptions and interpretations of meaning are described, and efforts to enhance trustworthiness are outlined. Study limitations and implications for health care practice, education, and research are elucidated, and concluding statements are presented. The first abstraction of meaning is presented next.

Shared Meaning # 1: Feeling Depressed

Feeling depressed is defined as feeling physical and emotional symptoms of depression, and communicating the symptoms of depression in American Sign Language (ASL) signs, gestures, and words. The shared concerns included (a) how depressive symptoms feel physically and mentally and (b) the signs and gestures used to communicate the depressive symptoms.

The participants were able to describe how depressive symptoms feel. The nine participants did not describe any symptoms of depression that were novel or unique, but symptoms appeared to parallel those well-identified in the literature (Ailey & Miller, 2004; Crogan et al., 2006). Most of the participants provided examples of their depressive symptoms that are identical to those outlined in the DSM IV-TR (American Psychiatric

Association, 2000) criteria for various depressive syndromes. The clinical definition of depression as a syndrome includes word usage such as depressed mood, loss of interest, loss of pleasure, loss of appetite, social withdrawal, sleep disturbances, alterations in concentration, and suicidal ideation (American Psychiatric Association, 2000; Goldberg, 2006). Although some participants did not specifically discuss mood, pleasure, or concentration, this is probably more reflective of the varied sophistication with vocabulary and ASL usage than the symptoms experienced or their understanding of depression. Universally, the participants offered descriptions of depressive symptoms in the ASL signs that were within their frame of knowledge. Essentially, this illustrates that the phenomena of depression is universally experienced.

The participants varied in their understanding of the written word *depression*, and in their use of the ASL signs used to express depression. Joan, Susannah, Norah, and Eileen clearly understood the word in written English and in signed ASL, and were each able to provide a concise definition of the word. Interestingly, these four participants also had additional words to qualify the nature of the depression. One ASL sign connoted vague depression, a different sign identified an intensity of depressive symptoms, and a third sign indicated severe or profound symptoms.

The findings about the varied understanding of the English-written and ASL sign for *depression* among Deaf adults are consistent with those noted by Steinberg et al. (1998b). Two participants appeared to understand both the finger-spelled word depression, and at least one ASL sign for depression, but did not demonstrate understanding when seeing the written English word. Maire, Ciara, and Brigid did not

understand any ASL sign for depression nor the word when finger-spelled, and did not appear to understand the written word.

The literature describes the high percentage of misdiagnosed Deaf patients in mental health settings due to miscommunication and misunderstandings (Carvill & Marston, 2002; Shapira et al., 1999). This study sample exemplifies the difference in the ability to communicate symptoms of depression. While some participants were able to provide a textbook definition of depression and then articulate their own symptoms, others utilized facial expressions, tears, slumped posture, and muted or agitated gestures to communicate what ASL signs could not. Even among several highly literate participants, it seems that in times of extreme depression, suicidal gestures were actually used as a means to communicate an intensity of feelings. It cannot be assumed that an absence of symptoms expressed by a Deaf adult indicates an absence of depression, but may indicate that the Deaf adult lacks the level of sophistication to communicate their depressive symptoms in written English or in ASL-signs. The next section describes the experiences that led to depressive symptoms.

Shared Meaning # 2: How Did I Get Depressed? – Emotional Chaos in My Life

Emotional chaos is defined as experiences of childhood, adolescence, and adulthood that led to depressive symptoms. Two shared concerns emerged (a) feeling different and isolated and (b) feeling abandoned. Common experiences included feeling different from other family members, feeling different from hearing children, feeling limited because of differences, feeling isolated from friends, feeling excluded and

isolated from conversations, feeling abandoned by parents, friends, or co-workers, and feeling abused.

Schotte et al. (2006), among others (Crogan et al., 2006; Goldberg, 2006) have reported that the risk for depression includes biology, psychological risk (i.e., trauma, maladaptation, and poor coping), somatic risks (i.e., somatic disease), and social-cultural risk (i.e., instability, insecurity). The findings from this study are consistent with the literature about psychological trauma, instability, and insecurity.

Psychological trauma began early for these participants, which is consistent with the early childhood trauma theories of depression (Higgins, 2003; Roberts & Hindley, 1999). Participants reported a profound sense of feeling or being different. This childhood trauma was a source of instability as it left the individual assuming there was something broken about him or her that caused others to move away. Eight described feeling different and set apart from their family at an early age. Although they appeared outwardly like others in the family, several grew up thinking that they were set apart because their ears were broken. Having broken ears necessitated numerous trips to the doctor's office; many recalled enduring frequent painful tests and examinations and even surgeries. As well-described in the literature (Koenes & Karshmer, 2000; Trask, 2004), children who grow up with chronic illness or disabilities frequently feel different and even feel broken; that is consistent with the findings from this study as the participants repeatedly reported feeling broken as children. When the hearing loss was not corrected, the feelings of being broken were intensified. Several asked the researcher to spread the

message to health care practitioners that self-esteem would have been vastly improved for these children had the hearing loss been accepted by family and practitioners.

Psychological trauma also occurred when participants were accused of not trying hard enough to hear; this is consistent with the literature illustrating that people with depression are accused of not trying hard enough to overcome their depression (Badger, 1996). Stories were related in which teachers accused the deaf child/student of not working, not paying attention, or not doing one's best. Sometimes parents reinforced that perspective by taking the child to the school psychologist or health care practitioner to find out what was wrong. The repeated message was that life would be better if the child could just work harder.

Consistent with many interpersonal theories of depression (Ailey & Miller, 2004; Higgins, 2003; Jackson et al., 2004), the Deaf participants' depressive symptoms were often reinforced by those within their social network. Many participants felt guilty for their deafness, which is consistent with feelings of guilt as a part of depression (Schotte et al., 2006); these participants believed that their parents' lives would be better if it weren't for the deafness. The majority of participants were children of divorced parents; a common concern was that the reason for the divorce was the child's deafness. In several instances, the participant articulated that the father or the mother blamed the deaf child for the divorce. Susannah shared her feeling of guilt surrounding a sibling's death. Although she could clearly outline how she could not have prevented the death, she brought up the topic whenever she described feeling ashamed and feeling depressed. Joan and Casey each described the death of a parent during their childhood, and each proposed

that they might have prevented the death in some way. Having such intense feelings of childhood must be considered as psychological risk. These findings are consistent with theories on early childhood trauma (Roberts & Hindley, 1999; Schotte et al., 2006; Taylor et al., 2000).

Social isolation may increase the risk for depression (Bain et al., 2004), and the findings in this study were consistent with interpersonal theories of depression. Eight participants described their childhood as primarily spent feeling isolated from other children or even siblings. With much emotion in voice and hand gestures, several proposed that their depressive symptoms today are a direct result of having felt isolated, alone, and broken throughout much of their life; their stories helped to illustrate their lack of social support. Most recalled having no common means of communication. These recollections were recounted with anger and hurt. Stories were narrated of deaf children being a witness to important events or conversations. Their words and phrases illustrate that they experienced these events as further isolating as they were set apart from their families and peers.

Early childhood trauma such as sexual or emotional abuse has been identified as increasing one's risk for depression (Sullivan & Knutson, 1998). The findings from this study were consistent, as three women described being sexually abused as children, two participants related their experiences of being physically abused, in each case by a parent, and one described emotional abuse. Typical of people in abusive situations, the participants hid their secrets out of fear or because they did not know who to turn to. While these early traumas were significant factors in the child's life, keeping these events

a secret further isolated the child and further depleted the sense of self-esteem, which is consistent with the literature.

While most participants described feeling different and even ostracized from hearing children, attending a residential school for the Deaf did not necessarily offer solace or enhance the sense of belonging. For every participant who attended residential school, there was a difficult and often painful period of enculturation in which the children were isolated, but this time from other Deaf children. This was consistent with the literature that children who move frequently or who move to a new cultural area are more apt to feel insecure (Wals & Verhulst, 2005). Until the deaf child was able to fully communicate in ASL, he or she was taunted by Deaf children. This would serve as a double assault on one's sense of feeling different; not only did the deaf child not belong to the hearing world but he or she did not fit in with the Deaf world either. This undoubtedly created further emotional chaos in the lives of the deaf children.

Just like all adolescents, adolescents who are Deaf experience sexual development and significant socialization during the adolescent period. The Deaf participants recalled that an additional difficulty with their adolescence was spending it in isolation. Many of the activities commonly expected and anticipated during adolescence were not happening for these participants, because of their perceived disability and the sense of being different. Descriptions included feeling lonely, missing out, and wanting a partner/boyfriend/girlfriend but feeling like such a relationship was impossible because of deafness. With the awareness that hearing people went out for dates, dances and parties

came the fear that these normal activities would never happen to the Deaf adolescent; this exacerbated the feelings of isolation and being broken.

Consistent with the literature (Lane & Bahan, 1998; Leigh & Anthony, 1999; Mitchell & Karchmer, 2006), communication in ASL was reported as a major impediment to relationships with siblings and parents. The participants internalized their families' lack of learning ASL as an indication that the family members could not be bothered. Interpersonal theories on depression (Mohan & Venugopal, 2000; Scheff, 2001) describe the lack of communication within a family as precipitating, maintaining, or exacerbating depression, while open and full communication within a family is supportive. In this study, the lack of communication led to feelings of low self-esteem, self-deprecation, and continual deflated sense of self-worth that current success and accomplishments cannot erase. For most participants, emotional chaos and distance from family continues today. Even when some participants related that they were avoiding family in order to avoid continued hurt, the tears and repeated statements that maybe the hearing person would learn to sign suggests the hope that things might someday change.

The childhood and adolescent experiences of these participants is not atypical of many hearing people's experiences of childhood and adolescence. Deaf participants have an accumulation of factors which taken together increase their risk of developing depressive symptoms. Being sexually, physically, or emotionally assaulted as a child is traumatic; having no one to turn to for help afterward is catastrophic. Feeling lonely as a child is undoubtedly hurtful, but feeling isolated from other children and one's own family is devastating. These profound feelings of isolation, abandonment, and abuse are

clear examples of psychological trauma, instability, and insecurity, and must be considered as potentially precipitating factors of depressive symptoms. The next section describes the participants' efforts to move beyond their emotional chaos.

Shared Meaning # 3: Reaching Out

Reaching out is defined as learning to walk in the Deaf world while also navigating the hearing world. Two shared concerns were observed (a) reaching out and hoping to be heard and understood by others and (b) reaching for the future. Common experiences that continually reinforced the lack of social support and exacerbated depressive symptoms included interpreter concerns, negative health care experiences, and continued searches for safety. Reaching to the future meant contemplating the future, wondering about relationships, and feeling afraid for the future.

Interpreters

The Deaf participants reached out to hearing individuals such as certified ASL interpreters in order to successfully navigate the hearing world. The interpreters helped to bridge the communication gap between the Deaf world and the hearing world, and some participants even described their relationship with an interpreter as more like a friendship or collaborative arrangement. However, the working relationship was also a source of angst and frustration, especially if skill levels were inadequate or concerns about confidentiality developed. Unsolicited comments and word usage such as *frustrating*, *necessity*, and *can't have a normal conversation without* illustrate the resentment at needing an interpreter. The resentment does not seem to be directed toward qualified

interpreters but merely at the Deaf person's perception that success in the hearing world necessitates an interpreter.

Health Care

The findings in this study are consistent with research showing that culturally Deaf adults do not have the same health care experiences as hearing people (DeVinney & Murphy, 2002; Pollard & Adams, 2004). Having a negative health care encounter caused some Deaf women to avoid any further health promotive examinations; this finding is consistent with the literature showing that Deaf women report negative or shameful experiences of health care (Ubido et al., 2002) and therefore avoid health promotion activities (Steinberg et al., 2002; Tamascar et al., 2000).

Consistent with the literature (Gilchrist, 2000; Mallinson, 2004), findings from this study showed that many Deaf adults left a health care encounter feeling stupid or feeling frustrated. Frequently, the encounter ended without the participant understanding their diagnosis or treatment plan, even for those with a high level of English reading comprehension; this furthered the feeling of stupidity. Frustration arose when the health care practitioner did not appear to understand the communication barriers or make enough effort to address these. Frustration was exacerbated when a Deaf adult felt concerned about his or her physical health but felt unsure as to how best to obtain the health care and information needed. Communication challenges and possible frustrations were outweighed by having a listener show interest in a Deaf adult's story.

Having interpreters present during a mental health interview may be unwanted by the patient (MacDougall, 2000; Osborne, 2003). That finding was noted by several

participants in this study. When the topic of therapy, counseling, psychiatry, or mental health care came up, several participants turned and apologized to the interpreter for not taking the interpreter to the practitioner's office. The Deaf participant then elaborated that although the communication with the health care provider is quite difficult and strained, it is less embarrassing than having the interpreter/friend present.

Deaf individuals are less apt to be asked about symptoms of depression (Tamascar et al., 2000). That finding was further substantiated by all study participants who declared they were never asked about any symptoms of depression by any health care practitioner. Each sought health care; even with frank manifestations such as loss of appetite, self-mutilation, loss of sleep, loss of interest, loss of concentration, and low self-esteem, the participants were not asked about their emotions or symptoms of depression. It is possible that they did not recognize their depressive symptoms, did not recognize it as a mental health syndrome that could be helped, did not know how to reach out for help, or even where to reach out for help. It is equally plausible that these participants assumed that if their provider did not specifically ask about symptoms, the symptoms were not worth mentioning.

Discussions of the past and the present often led to discussions of the future. While fear of the future is not a phenomenon unique to Deaf adults, their fears are probably intensified by their continued interactions with the hearing world. Fear was expressed when describing finances, jobs, being alone, and finding or keeping a life partner. Again, these fears are not unique to Deaf adults. However, feeling fearful of the future is undoubtedly intensified by communication barriers. Fear of the future may also

be moderated to an extent by feeling a sense of belonging. The final shared meaning of being a member of the Deaf culture is discussed next.

Shared Meaning # 4: I am Deaf – I am not Broken!

This is defined as identifying oneself as a member of the Deaf culture. Two shared concerns were noted (a) feeling proud to be a member of the Deaf culture and (b) promoting the Deaf culture. Belonging to the Deaf culture was associated with improved self-esteem and helped to reduce the feelings of being broken or stupid; ultimately, membership in the culture provided the greatest moderator for the symptoms of depression. Common experiences associated with acceptance into the Deaf culture included forming important relationships with other Deaf adults, and improved self-esteem. Teaching ASL, tutoring deaf/Deaf children and adults, and teaching about the Deaf culture were common ways of promoting the Deaf culture.

Membership in the Deaf culture may enhance one's sense of self-confidence, self-worth, and self-actualization (McDonald, 2006). For each study participant, there was a sense of pride at being a member of the Deaf culture. This was noted by stories recounted with a smile, at learning ASL, at participating in Deaf cultural community events, and at meeting other Deaf adults. All participants described the significant change in self-esteem and belonging once feeling a part of the Deaf community. For most participants, this acceptance marked the first time he or she ever felt a sense of belonging.

Being a part of the Deaf culture altered the self-perception of broken. As a part of the Deaf culture, the participants no longer feel the need to prove themselves. Membership frequently helped the participants move beyond feeling broken and isolated

and like giving up on their hopes and dreams. Positive outcomes of belonging included learning ASL, teaching ASL, and forming friendships with other Deaf adults, which also helped to restore the sense of self-worth. Belonging was further evidenced by the delightful humor displayed when narrating stories about being Deaf. Humor and pride was noted among the participants as they described the latest technological inventions and then teased the researcher for her lack of technological prowess.

Several participants made specific requests of information they wished to be shared with anyone interested. Joan asked the researcher to let educators know how terrible and futile it is to be sent to a public hearing school. Eileen wanted the researcher to disseminate her findings related to mental and physical health care to all practitioners, in order to increase their sensitivity toward any Deaf patients. Four participants wanted educators and health care practitioners to know that Deaf people are not broken or stupid. Sean asked any readers to consider Deaf people as unable to hear but not unable to do.

While these statements portray the sentiments of the various participants, they also reflect the lack of a voice or medium for Deaf individuals and the Deaf culture. The Deaf culture is centered around a unique and visual language, with a rich history and unique worldview (Research in Centre for Deaf Studies, 2006). It is the researcher's opinion based on observations and interactions with the nine participants in this study that the Deaf culture is also a source of emotional support, self-esteem, and pride. The following section further elaborates on the researcher's pre-conceptions.

Pre-Conceptions

In keeping with the hermeneutic philosophy and methodology, the researcher's self-reflections must be identified and brought into the analysis. The researcher anticipated based on the literature review, that the majority of participants would have a lower literacy rate and perhaps lower sophistication of ASL signs. In fact, her anticipation was completely incorrect. Six participants demonstrated a skill in ASL that challenged even the interpreters. The interpreters were challenged to come up with the spoken English word for several signed ASL words such as the varying degrees of depression.

The researcher's own pre-understanding of health care and depression caused her to be on the alert for signs or symptoms of depression. Before and even during each interview, she reminded herself that her role was that of researcher rather than diagnostician. During several early interviews, she found herself reacting to a specific health care statement with concern. For example, when Susannah related her attempted suicide, the researcher was distracted with the absence of health care during this crisis rather than listening to what was being said. During the second interview with this participant, the researcher was better able to be cognizant of her health care background and let the story unfold.

Sounds such as music, spoken words, and nature are very important to this researcher. When interviewing those who lost their hearing at a later age, she anticipated that the hearing loss itself might be a trigger for depressive symptoms. She became aware during several interviews that she was listening for signs of depression related to the

hearing loss. In fact, there was no evidence that the loss of hearing itself triggered depressive symptoms. Rather, it was the factors relating to the hearing loss such as isolation, feeling different, or having a loss of common communication that led to depressive symptoms.

The researcher was constantly reflecting on her own definition of normal. It became clear during the interview process that the participants had struggled with their concept of normal, and even with feeling different or abnormal. Although an interpreter was present throughout the interviews, the researcher found herself signing more frequently. An interesting transformation happened for this researcher; by the completion of the interviewing process, communicating in ASL felt normal and even quite comfortable.

As a practitioner with a 30-year history of health care, the researcher feels a great amount of pride in her role. She has worked with excellent practitioners and made the assumption that the participants' stories if shared, would all outline excellent health care experiences. Despite the illustrations in the literature, it was exceedingly difficult to have participants recount experiences of miscommunication, misunderstanding, frustration, hurt, shame, and embarrassment. The researcher found herself hoping that some of the more sophisticated communicators might provide examples of positive health care encounters. The final participant interviewed was Eileen, who is very articulate and easily understood; as she began to voluntarily describe her frustration in the health care setting the researcher felt disappointed. Self-reflection during this interview allowed the researcher to engage in Eileen's story. Continued self-reflection during transcription and

even analysis enabled the researcher to appreciate the participants' experiences for what they were.

Trustworthiness

The researcher followed the suggestions made by Fleming et al. (2003) to establish trustworthiness in hermeneutic research. Efforts to establish trustworthiness included auditability, credibility, confirmability, and objectivity. Auditability was evidenced by the researcher's identifying statements and providing written descriptions support and illustrate the statements. For example, an interpretation of an experience as depicting anger was supported by descriptions of facial expressions, exaggerated hand gestures, tears, and body language. Telephone, personal, and e-mail conversations occurred between the researcher and the dissertation chairperson, which aided the decision to interpret the various descriptions and phrases in a certain manner. One member of the researcher's dissertation committee has extensive experience conducting research with culturally Deaf adults; conversations with this committee member helped to verify accuracy of the interpreters' translations during interviews and provided ongoing feedback as to the researcher's skills and techniques during the interviews. These committee members reviewed the researcher's transcriptions compared with the DVD recordings, which further enhanced the researcher's skills and accuracy.

Confirmability was addressed by interviewing each participant three times. During the first interview, the participant was asked to relate their life story. Key phrases, concerns, and experiences that seemed important to the participants were identified and interpreted by the researcher, and these were further discussed and expanded during the

second interview. The second interview continued until saturation had been achieved. The third interview served to confirm that mutual understanding of central concerns had occurred. Recruitment and interviewing continued until it was apparent that saturation had occurred. Saturation was confirmed by discussion and agreement between the researcher and the dissertation chairperson.

Credibility was established in several ways. Direct quotations made by each participant were included in the narrative. Quotes were selected that best represent the participant's experiences, feelings, and emotions on a given topic. There was a vast difference in the sophistication of language among the participants; while quotations are included from every participant, some participant statements are more visible as data bits than others. In order to reflect the emotions and experiences of each participant, single words and short phrases were included in the text. Credibility was further enhanced by providing participants a one-page sheet taken from the Summary of Shared Meaning section of this manuscript. Four participants were given this sheet, and all agreed with the findings. As Nora expressed:

"It sounds like you got a good handle on the key points. Congratulations!"

Consistency was established by conducting all interviews in ASL, the most natural language of the participants. One researcher conducted all interviews. An unexpected event was that several participants asked to bring "their own" interpreter. Two interpreters were therefore used in this study, but each participant used the same interpreter for all three interviews to further ensure consistency. The next section discusses study limitations.

Study Limitations

Nine culturally Deaf adults volunteered to participate in this research study. Recruitment focused on the community of Reno, Nevada, and although some participants reside on the California border, they claim Reno as their community. Study limitations include the nature of the community and the nature of volunteering to tell one's story, the study sample, and the research method and investigator techniques.

The Community and the Nature of Volunteers

Although the Northern Nevada city of Reno is relatively large, the Deaf community is quite small. Most of the participants who contacted the researcher had heard about the nurse who wanted to talk to Deaf people. After the first participant completed her first interview, she told several others about the study and the opportunity to talk to a nurse who would listen. The interviewer emphasized her role as researcher rather than nurse or health care provider, but it is possible that the dual role may have biased those who volunteered to participate. A number of participants described anger at the government, with educators, and/or with health care providers. The motivation to participate in this study may also constitute a study limitation. As a number of participants expressly asked the researcher to vocalize their concerns, the study may have attracted more participants who wish to air their concerns.

Study Sample

As previously described in this manuscript and the literature, the level of reading comprehension and communication skills vary among culturally Deaf adults. Three participants appeared to have less sophisticated ASL sign usage and understanding, but

the majority of participants demonstrated a high level of sophistication and understanding of written English and ASL signs.

Limitations in Research Method and Techniques

This study is the first extensive piece of research undertaken by the investigator. The first interviews were scattered and less than organized, and the researcher's reactions to several statements may have distracted the participant from their focused narration. With the guidance of the dissertation chair and the Deaf researcher/committee member, the researcher's skills improved.

The researcher's initial expectation of the interviews was that she would begin by asking the participants to describe a time of extended sadness. She transcribed the interview and then sent the transcription to the committee. However, the researcher was so focused on protecting the participants that she failed to follow her protocol and erased several videotaped interviews before two dissertation committee members had reviewed the videotapes. She also did not transcribe each videotape precisely word for word. A telephone conference call with the dissertation chair and members of the committee helped to identify the failed protocol and the imprecise transcription. Further videotapes and transcriptions were reviewed by the dissertation chair and some committee members for the quality of the interview technique and accuracy in transcription. Based on guidance from the committee, all subsequent first interviews began by simply getting to know the participants. This improved the quality of the interviews, and led to a richness of data.

During the first few interviews, the researcher's own health care background may have been a limiting factor. The researcher reacted to several statements as if she were a health care practitioner rather than a researcher; for example, when a participant described her attempted suicide, the researcher started to focus on how no one reached out to help the participant rather than let the participant's story unfold in her own way.

Each participant was interviewed three times. Inevitably, there was a change in behavior and affect between the first and third interview. While several participants appeared reluctant to interact and even muted and disinterested initially, they seemed eager to communicate by the third interview. More eye contact was noted, and smiles or even laughter was frequent. During the earlier interviews, this may have stemmed from the researcher's focus on sadness rather than in getting to know the participants. All participants asked to hug the researcher at the end of the third interview, and many asked for a hug at the end of the second interview. Several related eagerly looking forward to a second and third interview. While the research method was to be a qualitative exploratory study, having an interested person inquire and attend to one's story can also be seen as an intervention. The nature and intensity of the emotions described may have been altered somewhat over the course of time spent with the researcher.

Implications for Nursing and Health Care

First and foremost, culturally Deaf adults are not stupid, broken, or damaged. They communicate in a visual way that is different from hearing people, and the lack of verbalization should never be seen as a reflection of literacy, intelligence, or understanding. Health care practitioners must remember that just as not all hearing people

have the same literacy rate and linguistic skills, not all Deaf adults read, write, or comprehend at the same level. In order to best assess culturally Deaf adults at risk for depression, the level of comprehension and communication must be assessed as one would for any non-Deaf patient.

Communication in Practice

Even for those who describe themselves as quite adept at lip-reading, much of the context of conversation is missed. When conducting an examination or procedure in which the practitioner's face may be hidden from view, some other method of communication should be considered. Communicating with the Deaf patient beforehand, explaining any procedure, and then asking the Deaf patient how they could best have their communication needs met during the procedure may help to reduce pain and fear. Assessing the differences in culture can help to identify the Deaf patient who would prefer to communicate via written English, via certified interpreter, or via lip-reading. Asking the patient what he or she prefers will enhance the health care experience.

Assessing Depressive Symptoms in Clinical Practice

As previously discussed in the literature and in this manuscript, depression index screening tools should not be considered as valid or reliable for all members of the Deaf culture. If at all possible, communication between practitioner and Deaf patient should be used to ascertain depressive symptoms; the method of communication should be comfortable and understandable for the Deaf patient. The participants in this study illustrate their reticence at volunteering symptoms of depression. Hearing patients are routinely screened for depression in the primary care setting; likewise Deaf patients

should be asked directly about any symptoms of depression. It is apparent from the various descriptions of the participants that not all Deaf adults connect their symptoms of fatigue, sadness, loss of appetite, loss of interest, ruminations, or sleeplessness with depression. Inquiring about specific symptoms may produce more accurate responses.

As children, most of these participants had undergone significant isolation and many had even experienced trauma. The practitioner should attempt to inquire as to the patient's childhood and environment, as well as childhood friends, family support, and school years. It is the experience of this researcher based on her interactions with the participants that they are forthright and willing to relate their stories, even if embarrassing or shameful.

Depressive symptoms among culturally Deaf adults appear to manifest in the same way as among hearing people. The methods of relating these depressive symptoms may vary, and the level of understanding the term *depression* certainly varies. Deaf adults may demonstrate facial expressions and gestures that are quite acceptable and normal among other Deaf adults, and such gestures or facial expressions should not be presumed to be a manifestation of a psychiatric syndrome.

Nursing stresses a holistic framework of health care. The nurse may feel constrained with time to provide holistic patient care to a Deaf adult. As evidenced by the participants in this study, being fully present and striving for understanding are key components of quality nursing care. Holistic health care includes not just eliciting a chief complaint and addressing it but reflecting, considering, and even searching for additional

elements of the patient's life experience. As the hermeneutic narratives showed, the participants in the study wanted to relate their experiences and share their emotions.

Summary of Implications

To honor the request of the participants, the researcher will continue to disseminate her research findings to health care practitioners via symposium presentations and manuscript submission to health care journals. The participants have asked the researcher to emphasize that Deaf people are not broken or stupid or damaged. The participants do not expect practitioners to master ASL or even communicate in finger-spelling, but they ask for ample time to interact with practitioners in order to better assess the unique behaviors, qualities, and characteristics of the individual.

Implications for Future Research

The findings from this study illustrate the need to develop and test a depression screening tool that is culturally valid and reliable for the population of Deaf adults.

In order to establish instrument validity and reliability for the general Deaf population, samples must be taken from populations beyond well-educated college students. Administering a depression screening tool to Deaf adult individuals with varying literacy rate might reflect more of the Deaf population.

A quantitative study could help to further illustrate the disparities in mental and physical health care for culturally Deaf adults in order to examine risk factors for depression. Determinants of individual vulnerability and risk of adverse health includes disparities within a social or geographic setting (Dever et al., 1988), and lack of social justice may render individuals more vulnerable to even minor psychiatric illness

(Elovainio et al., 2002). As a social group, culturally Deaf adults have limited resources, such as health education (Gilchrist, 2000; Harmer, 1999; Mallinson, 2004) and health insurance (Harmer, 1999). Critical ethnography might identify disparities and serve as a method of effecting change.

Intervention studies such as Participatory Action Research and Community-based Interventions could help to maximize assessment of Deaf adults at risk for depression. Community-based interventions could emphasize education to Deaf adults, specifically by describing depressive symptoms in terms that have cultural meaning. Educational efforts should include reducing the stigma of depression among this population.

Conclusions

This qualitative hermeneutic study provides a description of the ASL words and meaning of depressive symptoms among nine culturally Deaf adults. Depressive symptoms appear to manifest similarly among Deaf and hearing individuals. ASL phrases and words used to communicate depression were varied, and the level of understanding the term *depression* was equally varied. Hearing and Deaf individuals share common childhood experiences such as sexual abuse, emotional abuse, physical abuse, feelings of isolation and loneliness, and even abandonment or feeling different; these may inevitably trigger depressive symptoms among all individuals. The Deaf adult's feelings and experiences must be considered as intensified by the communication barriers. Further isolation from family members, peers, colleagues, and health care providers exacerbates the lack of social support and may sustain the symptoms of depression. Membership in the Deaf culture reduces the sense of being different and provides improved self-esteem;

this may ultimately be the vehicle that helps a Deaf individual pull through his or her depressive symptoms.

Relying on depression screening instruments as a means to assess depression among culturally Deaf adults is inadequate, and additional methods of eliciting symptomatology must be employed. Earlier and more accurate means of assessment can enable more prompt treatment, thereby reducing mental health disparities to this underserved population.

APPENDIX A: HUMAN SUBJECTS APPROVAL

Human Subjects Protection Program

19 February 2007

Kate Sheppard, PhD candidate
 Advisor: Terry Badger, PhD
 College of Nursing
 PO Box 210203

THE UNIVERSITY OF
ARIZONA[®]
 TUCSON ARIZONA

1350 N. Vine Avenue
 P.O. Box 245137
 Tucson, AZ 85724-5137
 (520) 626-6721
<http://www.irb.arizona.edu>

RE: **BSC B06.177 DEPRESSIVE SYMPTOMS AMONG CULTURALLY DEAF ADULTS**
[NEW TITLE]

Dear Ms. Sheppard:

We received your letter and accompanying revised Consent Forms, Project Review Form, recruitment flyer, and interview questions for the above referenced project. Permission is requested to:

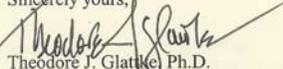
- increase the enrollment to 8 participants.
- broaden the inclusion criteria to participants 21 years and older.
- increase the study visits to three interviews.
- refine the data analysis to hermeneutic phenomenology.
- revise the study title to *DEPRESSIVE SYMPTOMS AMONG CULTURALLY DEAF ADULTS*.
- revise the recording of the interviews from video or audio to video.
- develop a DVD that translates the U of A approved written consent in American Sign Language [please submit for review prior to utilization].

These changes do not impact subject safety. Approval of these changes is granted effective 19 February 2007

The Human Subjects Committee (Institutional Review Board) of the University of Arizona has a current *Federal Wide Assurance* of compliance, number *FWA00004218*, which is on file with the Department of Health and Human Services and covers this activity.

Approval is granted with the understanding that no further changes or additions will be made either to the procedures followed or to the consent form(s) used (copies of which we have on file) without the knowledge and approval of the Human Subjects Committee and your College or Departmental Review Committee. Any research related physical or psychological harm to any subject must also be reported to each committee.

Sincerely yours,



Theodore J. Glattke, Ph.D.
 Chair, Social and Behavioral Sciences Human Subjects Committee

TJG:md

cc: Departmental/College Review Committee



THE UNIVERSITY
OF ARIZONA.

Human Subjects
Protection Program

1235 N. Mountain Ave.
P.O. Box 245137
Tucson, AZ 85724-5137
Tel: (520) 626-6721
<http://irb.arizona.edu>

17 August 2007

Kate Sheppard, PhD candidate
Advisor: Terry Badger, PhD
College of Nursing
PO Box 210203

RE: **BSC B06.177 DEPRESSIVE SYMPTOMS AMONG CULTURALLY DEAF ADULTS**

Dear Ms. Sheppard:

We received your letter dated 5 August 2007 and accompanying revised American Sign Language translation of the Consent Form [DVD version] for the above referenced project. Permission is requested to:

- utilize the American Sign Language translation of the approved version of the Consent Form

These changes do not impact subject safety. Approval of these changes is granted effective 17 August 2007.

The Human Subjects Committee (Institutional Review Board) of the University of Arizona has a current *Federal Wide Assurance* of compliance, number *FWA00004218*, which is on file with the Department of Health and Human Services and covers this activity.

Approval is granted with the understanding that no further changes or additions will be made either to the procedures followed or to the consent form(s) used (copies of which we have on file) without the knowledge and approval of the Human Subjects Committee and your College or Departmental Review Committee. Any research related physical or psychological harm to any subject must also be reported to each committee.

Sincerely yours,

Theodore J. Glatke, Ph.D.
Chair, Social and Behavioral Sciences Human Subjects Committee

TJG:md

cc: Departmental/College Review Committee



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