Communication Experiences of Deaf and Hard-of-Hearing People Facing the Death of a Loved One

by

Linda Marguerite Franchi

M.A. (Renaissance Studies), University of London, 2001
B.A. (Psychology and Deaf Studies), Antioch University Seattle, 1994

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Approval

Name: Linda Marguerite Franchi
Degree: Doctor of Philosophy
Title of Dissertation: Communication Experiences of Deaf and Hard-of-Hearing People Facing the Death of a Loved One

Examinining Committee:

Chair: Dr. Daniel Laitsch
Associate Professor

Dr. Carolyn Mamchur
Senior Supervisor
Professor

Dr. Stewart Richmond
Supervisor
Professor and Director, Undergraduate Programs

Dr. David Paterson
Internal/External
Associate Dean, Administration

Dr. Janet Jamieson
External Examiner
Professor, Department of Educational & Counselling Psychology, & Special Education
University of British Columbia

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Abstract

Communication barriers prevent Deaf and hard-of-hearing individuals from participating in the dying process with their loved ones. Using arts-based research, this enquiry examined end-of-life communication, situations of death, and rituals for closure by capturing video-taped narratives in American Sign Language. Deaf and hard-of-hearing participants provided candid and moving portraits of their experiences with health care workers, extended family, and funeral and memorial events. Their narratives formed the basis for a fully accessible American Sign Language, sound, music, voice, and captioned documentary film entitled, Talkable.

Excluding Deaf and hard-of-hearing people from participating in end-of-life processes with those they love has a serious impact on their ability to process their grief and integrate their loss. The research found Deaf and hard-of-hearing mourners need specific resources surrounding death and loss to prevent further trauma or wounding. In particular, they need access to health care and funeral industry professionals who are familiar and sensitive to the social and cultural issues affecting end-of-life issues. Hiring American Sign Language interpreters for anyone facing the death of a loved one or facing death themselves is essential for receiving adequate information and communication.

Deaf, deafened, and hard-of-hearing individuals need accessible services whether they are the receivers of care or family members of those receiving care. Ideally, training Deaf and hard-of-hearing support workers in end-of-life processes and palliative and hospice services would provide the necessary linguistic and cultural components that hearing individuals accessing health care receive.

Keywords: American Sign Language; Deaf, hard-of-hearing, audiological; communication and cultural barriers; linguistic and cultural differences; death and dying; grieving, bereavement, end-of-life care
Dedication

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Chapter 1.

Introduction

When I began this journey into death, I was fairly clear about my question: How do Deaf and hard-of-hearing people cope with death when they are overcoming language barriers?

The hearing loss of most members of the signing community has proven disastrous for them because it has played into the hands of those who seek to dispose of social problems by medicalizing them.1

(Lane, 1984, p. xiii)

Accepting the death of a loved one and facing one’s death is hard enough for hearing people who have the dominate discourse, language and hearing to navigate the terrain of dying and death. It strikes at the very core of our humanity and affects us all indirectly and of course, directly as we come face-to-face with our own time-clock, functioning as pretend time-keepers in the broader context of our lives. Death and dying is a profound and personal process, making it a difficult topic to write about particularly when the death of a loved one stops at your door unexpectedly.

Death is the least talked about truth in Western society, yet we are inundated with experiences, stories and images of death everywhere we look. How is it then that death being an intrinsic part of life remains taboo in Western culture? We have no

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1 *When the mind hears* is a historical analysis of the Deaf community, sign language and the history of education of the Deaf. Dr. Lanes premise is that Deaf people need to be viewed as a cultural and linguistic minority, rather than individuals with defective hearing. Hailed as a guru and an advocate, he has written extensively for the need of Deaf people to challenge the socially constructed definition of what Deaf means versus disability.
control ultimately of thwarting this truth and in the stillness of our lives we all meet death. No topic is held back from public display and discussion, except death. Death is something we do not want to acknowledge, and become a death-denying society.

A society which is shy of death is also likely to be rattled by foreigners. Both mark out the limits of our lives, relativizing them in palatable ways. But in one sense all others are foreigners. My identity lies in keeping with others, and this—because they perceive me through the thick mesh of their own interests and desires—can never be an entirely safe keeping.

(Eagleton, 2004, p. 212)

When I first discussed loss and death of a loved one with Deaf and hard-of-hearing community members, my experience was that it was very truncated, matter of fact, almost without emotion. A particular experience prompted me to ponder the response to death. Extending condolences to a Deaf community member who had lost her mother left me curious. We were conversing and I offered the following in sign language. “Sorry about your mother.” Her response to me in sign language was “Gone accept.” She looked away and down.

At the time, I was unsettled by this response and yet accepted it, as I thought this was unique to her. However, I began to see this response over and over again and realized I wasn’t satisfied by this response. There ought to be more, something else. This was a common cultural response and I, essentially an outsider, could never quite enter that world.

Imagine if you will, two circles, representing two cultures one Hearing and one Deaf (see Figure 1). The circles move towards one another and overlap. It is in the overlapping that the third culture is created and exists from day-to-day. The author has full membership in hearing culture and belongs to a broader community of Deaf people without full membership. I am fluent in American Sign Language (ASL). This means that I am able to comprehend Deaf and hard-of-hearing individuals’ discourse and also I am able to express myself in sign language. Nonetheless, Sign language is my second language and it requires my full attention and orientation visually, rather than depending on auditory information. Because of this audiological difference, I cannot belong to the core Deaf community regardless of my political and professional associations or values and beliefs.
Close Deaf and hard-of-hearing friends not with standing, I stand on periphery of the culture looking in, subjected to the wide brush stroke of being a hearing oppressor because of my audiological status and the privilege that is associated with that status.

Growing is the human way of living, and death is the final stage in the development of human beings. For life to be valued every day, not simply near to the time of anticipated death, one’s own inevitable death must be faced and accepted. We must allow death to provide a context for our lives, for in it lay the meaning of life and the key to growth.

(Kübler-Ross, 1975, p. 7)

According to Elizabeth Kübler-Ross (1975), death is the final stage of growth. Death is only the end of the physical body, but our spirit still lives on. It is trying to

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2 Hearing culture has specific cultural and linguistic norms. Deaf culture has specific linguistic and cultural norms as well. Interfacing between the two cultures linguistically and socially creates invisible bridges. It is when individuals are able to function well in both worlds and in both languages and culture in their own right that a third culture emerges. One is neither fully participating in one culture or the other. Knowledge and experience in both cultures blends fragments of each culture into a perspective that is often referred to as third culture.
conform to the external definitions of who we are that spells our spiritual death. Each of us is unique, but we try to fit into stereotypes, culturally defined for us.

To contemplate our own death requires courage and a willingness to stick with it. This task is often wrought with emotional undercurrents that lead the sojourner to travel uncharted territory with often extraordinary consequences. The Tibetan proverb succinctly captures the task of confronting one’s death and the death of a loved one: “You cannot discover new oceans unless you have the courage to lose sight of the shore.”

Think about your own death. How much time and energy have you put into examining your beliefs, feelings, hopes and fears about the end of your life? What if you were told you had a limited time to live? Would it change the way you’re presently conducting your life? Are there things you would feel an urgency to do before you died? Are you afraid of dying? Of death? Can you identify the source of your fears? Consider the death of someone you love. What would you talk about to a loved one who was dying? (Kübler-Ross, 1975, p. 14)

If we could address the certainty of death candidly, would it provide essence and sustenance for the journey-of-life? Would we arrive at meaning? Why is it that we learn to love and attach, only to let go and experience loss and eventual death? Why then is death important to students? Is it important and should it be? These questions are certainly not original. Philosophers, political theorists, theologians, psychologists, educators and artists each in their own tradition have pondered and discerned the meaning of life and death.

Maxine Greene swirls around and begins to resonate as I engage in the questions of how Deaf and hard-of-hearing individuals deal with the eventuality of death.
She eloquently articulates “that the ultimate purpose of education is to help students and teachers create meaning in their lives” (cited in Shaw & Rozycki, 2000, p. 2).³

Greene continues to plant the seed of personal awareness and consciousness as a metaphor for action and meaning on how skills and knowledge are acquired when she writes:

Education at its best is a process of teaching individuals to explore ideas about themselves and the world in which they live, to ask questions about the experience called living and to embrace ambiguity, to notice the unusual without fear and to look upon the ordinary with new eyes.

(Greene as cited in Shaw & Rozycki, 2000, p. 2)

I witnessed the isolation experienced by Deaf and hard-of-hearing community members as they assisted a loved one at the time of loss. I reflected on the process of communication and language and cultural barriers affecting Deaf and hard-of-hearing individuals as they come to terms with their death or the death of a loved one. I pondered this question deeply. If one were to awaken to a very big life transition such as death, would this then act as a catalyst for the potential of creating meaning in their lives?

In ASL, a Deaf man relayed a childhood story. His father died suddenly when he was a teenager. No one spoke to him about the sudden disappearance of his father. “I was not informed of the funeral; they just left me at home.” In his mind, it was because no one knew how to communicate with him. This experience was a source of unresolved grief until he too died a few years ago. He often returned to his script of the funeral, the one that took place without him. In some way he was not able to fully integrate the painful loss of his father, because he was disenfranchised from the process of shared grief, ritual and closure often connected with funerals.

³ A synopsis of Maxine Greene’s Educational Theory has been analyzed in eight categories by Shaw and Rozycki. They are: theory of value, theory of knowledge, theory of human nature, theory of learning, theory of transmission, theory of society, theory of opportunity, and theory of consensus.
The unfinished business associated with the death of his father and the communication barriers he faced were reminders to me about access to communication and how important integration of loss associated with death affects one’s well-being. In this case, at the center of his core identity was ASL. His position in his family and society was likened to being a foreigner in his own family and country without the removal of communication barriers. He was isolated and not part of his family. This story has been repeated by others, although the characters, protagonists and plots are different. The common theme is of exclusion and isolation.

A hard-of-hearing woman who relied primarily on hearing-aids and lip reading to make her way in the world had a similar texture and thread to her narrative. She recounted the final weeks of her mother’s illness and death from cancer. She openly discussed the frustration and the exclusion she felt at not knowing what was going on with family communication around the mother’s hospital bed.

Her mother’s deterioration and her own hearing loss created a communication barrier. She was not able to hear the whispers of her mother. Her primary disappointment and ensuing distress was the medical professional’s habits and family’s practice of not relaying what they were saying to each other. When they gathered at the mother’s bedside, the hard-of-hearing woman was isolated from other family members and could not participate in the rituals of saying goodbye to her mother.

When someone you love is dying or dies the world as you know it changes. The physical and emotional reactions to the situation can at times, seem overwhelming and unmanageable.

Her family did not communicate information when she asked, “What was being said?” They would tell her, “It wasn’t important.” She tearfully relayed that it was crucial to her process that any communication between any of the family members, nurses and doctors, and her mother was important. She wanted to be included in it all. She didn’t want to miss out because she was Deaf. “It would have been so helpful for me if they included me in their conversations. That way I wouldn’t have felt so alone.”
Her understanding and acceptance of what was happening at the time was contingent on information. In her heart, all communication was important for her to feel a part of the process and connected to her family and the medical professionals.

Deaf people have been viewed in our society from a medical perspective which places the focus on hearing deficits that need to be fixed rather than viewing Deaf people as members of a cultural and linguistic minority community. Because of their differences, they need to deal with death not only on the emotional realm but also on the linguistic and cultural landscape.

Deaf people communicate not the sensory experience of silence but rather the values of Deaf culture. These include the beauty of Sign Language and its painful oppression, the breakdown of family life when hearing parents cannot communicate in Sign Language, the joys of Deaf bonding and the abuses of audiology when the Deaf difference is treated as deviance. (Schertz & Lane, 1999, p. 20)

Every linguistic and cultural group has its own way of seeing and expressing how it experiences and interprets the world and interacts with it. How best to capture the essence of the responses of Deaf and hard-of-hearing individuals in these circumstances? I wanted to capture their language and narratives as naturally as possible.

As a film maker—I felt a documentary might be the most appropriate method. I would interview Deaf individuals and visually record our conversations. The documentary would be useful as a teaching tool for both Deaf and hard-of-hearing individuals to better understand themselves and for hearing populations to understand the communication needs related to the death of a loved one and in some cases their own dying and death.

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4 Brenda Schertz was born Deaf in a Deaf family and is a member of the Deaf Community. She organized her first exhibit of Deaf culture Art in 1993, and is a co-director of the First National Touring Exhibit of Deaf Culture Art. Harlan Lane is hearing and is the other co-director of the touring exhibit. He is a strong advocate of culturally Deaf people. Among his published books are *When the mind hears* and *The mask of benevolence*. 
The documentary could be used for education and training in the health care profession. Families and loved ones could gain insight. Service providers, bereavement centers and grief and loss centers, medical professionals, hospices and palliative services that are either providing direct service or assisting those facing end of life issues are available to the hearing population. Education means creating meaning in our lives.

I proceeded with the task of making the documentary. I chased funerals, I interviewed friends and acquaintances, I edited, I directed and I produced. As I created this art form, I was engaged in art-based research. I thought at that time, that the burning question was clear: how did the barriers of access to language affect the way Deaf and hard-of-hearing individuals deal with death and dying?

Why wasn’t I satisfied that this was enough? From the narratives mentioned above, it was clear to me that because of communication barriers, they felt they were excluded from full participation in the end of life stages of their loved ones. I wanted to further explore this theme. Capturing their experiences visually demanded defining the goal and examining the barriers for achieving it. Tackling this topic systematically with Deaf and hard-of-hearing individuals was a leap of faith into the unknown with changing realities.

Martha E. Zacharias (2004) summarizes the effects of engaging in ever-changing realities in her article, “Moving Beyond with Maxine Greene: Integrating Curriculum with Consciousness” when she addresses Greene’s postmodern observations of engagement:

Greene acknowledges that a human being may feel strange, disengaged, frustrated, and/or helpless in the face of ever-changing realities; and that a willingness to acknowledge the strangeness, the uncertainty, is part of learning. An individual may be aware that her sense of reality will depend on, and vary with, perspectives taken, and this may bring increased fragility to attempts at creating order and harmony in the life-world.

(p. 143)

Because hearing loss is primarily a communication difference, it affects both the individual who has it and those with whom he or she interacts. If the listener is hard-of-hearing and does not understand what is being said, the person speaking will also
experience a communication problem. In the same way, speakers, as well as listeners who are hard-of-hearing, share responsibility for preventing or reducing communication problems related to hearing loss. Individuals who are hard-of-hearing cannot prevent or resolve communication problems by themselves; they often need the cooperation of those with whom they communicate.

So I set out on a journey of exploring the theme and better understanding how Deaf and hard-of-hearing people are affected by language and barriers. Exploring the theme would assist me in understanding how Deaf and hard-of-hearing are prevented direct access to their loved one. My daily companions became writings on death, the experiences of the death of others, whether they were friends, family or those dying clients I served as a member of my profession.

Ours is a death denying society. We hide it behind the sterile walls of the hospital and the cosmetic mask in the funeral home. But death is inevitable and we must face the question of how to deal with it. Why do we treat death as a taboo? What are the sources of our fears? How do we express our grief and accept the death as a person close to us? How do we prepare for our own death? (Kübler-Ross, 1975, p. 13)\(^5\)

I went to the people directly. I listened to Deaf individuals with my eyes and hard-of-hearing individuals with my ears. I watched their stories emerge and their hands telling the stories through the air. It was a profound experience observing and at the same time being present, attending to the narratives as they told their stories in ASL.

If you talk to a man in a language he understands, that goes to his head. If you talk to him in his language, that goes to his heart.

(CNN, 2008\(^6\))

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\(^5\) Elisabeth Kübler-Ross was a pioneer in creating public awareness of the needs of dying people. As a trained Swiss psychiatrist she wrote *Death and Dying*, and developed the model of The Five Stages of Grief. She authored more than 25 books related to coping and caring for people who are dying.

\(^6\) A memorable Nelson Mandela quote.
But what emerged was even a greater question: How do I deal with death and dying? I had ignored the big question: Why was I so drawn to the story of death?

When entering this doctoral program, I had no plans of researching death. I am an educator, artist and administrator. As a child I did not experience any specific deaths or even a community tragedy that prompted an awareness of death. I did experience losses associated with childhood: the loss of my guinea pig, Precious, and our spider monkey, Coca, when I was seven. The death of my pets didn’t catapult me into scholarly research on death nor the differences between how Deaf and hard-of-hearing people are affected by death.

I was so drawn to the story of death because my personal life had changed, dramatically so, when I entered the doctoral program. I turned 50 that spring, and within weeks of starting classes, two significant deaths arrived unexpectedly at my doorstep. My mother and my long-term therapist (surrogate mother) died within weeks of each other without warning.

I came face-to-face with a terrible anguish that brought me to my knees. My sense of the world became muted. I went through the motions of everyday life challenged to understand the emotions and integrate the grief. I found myself writing every day and consumed with learning about grief. I had experienced grief associated with death before the fall of 2008.

My sister and father died years ago and I was graced with two years between each of them. Losing my mother and Lorie within weeks shattered my wholeness. Looking back I must have lost time and location. I have very little recollection of that period except sorrow. I am so grateful for the daily writing and healing that followed during that year. Just as my senses for life began to return and I could feel and appreciate the warmth of sunshine beating on my face, my long-time friend and cabin partner died at 51 years old. Again, his death was totally unexpected.

David was also involved in the Deaf and hard-of-hearing community as an educator. His death affected all of us and had a deep impact on the Deaf community. I began to see that exploring the theme of death was significant for me.
Initially, I had ignored the big question: why was I so drawn to the story of death? In the process of exploring this theme with Deaf and hard-of-hearing community members I was returned to my story of death and graced with a revelation about relationships and how essential they are to our well-being.

Death is both alien and intimate to us, neither wholly strange nor purely one’s own. To this extent, one’s relationship to it resembles one’s relationship to other people, who are likewise both fellows and strangers. Death may not be exactly a friend, but neither is it entirely an enemy. Like a friend, it can enlighten me about myself, though like an enemy it does so in ways I would rather not hear or see. It can remind me of my creatureliness and finitude, of the fragile, ephemeral nature of my existence, of my own neediness and vulnerability of others.

The process of learning, of moving beyond, calls for an inherent focus for the learner: “ordering the materials of his own life-world when dislocations occur, what was once familiar abruptly appears strange” (Zacharias, 1997, p. 142). The contemporary person deals continuously with the transience of her life-world, of the manner in which she relates to people, ideas, art, and values (Zacharias, 1997).

Deaf people who use ASL are part of a larger community that has a core identity based on its linguistic and cultural traditions. That culture is commonly known as Deaf culture; sharing common values, norms, traditions, language and identity. Deaf culture then is rooted in a visual culture. This is evidenced through the many values expressed through their visual language (ASL), and most activities related to their culture.

In his Foreword to the book, Living with grief: Diversity and end-of-life care, Richard Payne, M.D., writes:

The distinctiveness of culture, language, social circumstance, religion, personality and gender are key foundations by which individuals find meaning and purpose in their living and dying and come to terms with the loss and remembrance of family and loved ones.

(Payne, 2009, para. 3)

I needed to explore whether communication barriers prevent Deaf and hard-of-hearing people from completing these essential components of end of life stages. I
addressed the existential questions of individuation, immortality and mortality and meaning, which brought closure and meaning to their lives. There is also beauty in loss. The death of a loved one is cause for suffering and also great joy. To experience loss and sorrow is to acknowledge that you attached and have loved, and that in itself is a gift.

Deaf and hard-of-hearing individuals experience additional needless suffering as a result of communication barriers. At times of distress when families often are supporting each other, Deaf and hard-of-hearing individuals feel even more of an outsider to their family and to the grieving and end of life process when communication breaks down.

My work drew to a halt while immersed in material related to death. The documentary I was attempting to analyze for my Chapter 4 was becoming more about me than about my subjects. And then life gave me a strange gift. My mentor and dear friend became stricken with ovarian cancer and I became chief caregiver. Dr. Maureen Donald is 93 years old. She is both an elder in the Deaf community and in some respects is viewed as a national icon. Maureen was the first Deaf teacher in British Columbia, an active educator for 33 years at the Jericho Hill School for the Deaf, developed the first Canadian Sign Language dictionary, and made a significant impact for decades on the graduate students enrolled in the Teacher of the Deaf program at the University of British Columbia. The contribution by Maureen in the field of Education was recognized by the University of British Columbia. Maureen was awarded the prestigious honour of an honorary doctorate in 2000.

She founded the Happy Hands Club for Deaf and hard-of-hearing seniors, which just finished their 20th anniversary. She has been and continues to be a leader in current affairs and all matters related to Deaf and hard-of-hearing communities. Dr. Maureen, as I affectionately refer to her, managed to navigate both the hearing and Deaf worlds with purpose, meaning and grace.

I knew this was part of my journey as an art/o/grapher. I began to record our times together. I had two new subjects. A Deaf mentor and friend facing end of life issues and me, a hearing care giver. This naturally evolved into an analysis about our
relationship. While caring for her at this difficult time in her life, the essentials of communication in the face of dying and death became crucial to her life experience.

What also emerged from this process was a second work of art: a collage of being with a person you love as they are losing their grip on life. I also was experiencing first-hand the needs of an elderly woman, who was Deaf, who uses ASL, and the obstacles and challenges she was faced with because of the language barriers. In our relationship, I moved from understanding the other to understanding the self.

The experience of navigating with Maureen as she tried to make her way through the barrage of systems related to the health care, chemo, doctors and caregivers was enlightening. The Deaf community is primarily a visual community that uses a visual language (ASL) to express and receive information. In fact, for most individuals who use ASL, the use of English is their Second Language.

Seeing first-hand the experience of a Deaf person, who uses ASL, trying to navigate illness and the processes associated with diagnosis, treatment, and prognosis was eye opening. In my mind, it made the work of the PhD imperative and timely. Not a minute more should pass before we provide access to communication for those facing end of life transitions or confronting the death of a loved one. Death and dying is hard work.

This process affected my personal landscape. Clearly, Maureen’s needs shed light on where my ‘meaning’ was located. I found it alongside the Deaf community, doing service of an extraordinary nature for which we both received immeasurable gifts, and for that I am grateful.
Because death is an essential part of life, to be fully alive is to be prepared for it. (Woodman, 2000, p. xv)

For me to answer the question of how Deaf and hard-of-hearing individuals cope with the death of a loved one, I had to come to terms with my understanding of death and loss.

Once again, I needed to go back to the literature and do more reading and searching. This time it was focused with a different lens. As I read and wrote I became aware of and examined my own emotional reactions to these sudden deaths and life circumstances that had arrived at my doorstep.

The stillness of time allowed my unconscious material the space to make its way from the depths of my being, to consciousness. To say that it was uncomfortable is an understatement. At times it felt shattering to my sense of self and I wondered who I was.

To be authentic I needed to find my voice. I spent 6 weeks in gestation, taking the time to reflect and be with myself from the inside out. The soul uncovered and shifted as it unearthed unconscious and conscious material connected to my identity and death.

**The Invitation**

*It doesn’t interest me what you do for a living. I want to know what you ache for and if you dare to dream of meeting your heart’s longing.*

*It doesn’t interest me how old you are. I want to know if you will risk looking like a fool for love, for your dream, for the adventure of being alive.*

*It doesn’t interest me what planets are squaring your moon... I want to know if you have touched the centre of your own sorrow*

---

7 This book is about living, not dying. It is about dying into life. When diagnosed with cancer, Woodman discovered how much dying it takes to get here, here into her body, here onto earth. It’s about the soul work required to heal both. Her personal journey is a story of individual transformation.
if you have been opened by life’s betrayals
or have become shrivelled and closed from fear of further pain.

I want to know if you can sit with pain, mine or your own
without moving to hide it, or fade it, or fix it.

I want to know if you can be with joy, mine or your own
if you can dance with wildness and let the ecstasy fill you
to the tips of your fingers and toes without cautioning us
to be careful, to be realistic, to remember the limitations
of being human.

It doesn’t interest me if the story you are telling me is true.
I want to know if you can disappoint another to be true to yourself.
If you can bear the accusation of betrayal and not betray your own soul.
If you can be faithless and therefore trustworthy.

I want to know if you can be with joy, mine or your own
if you can dance with wildness and let the ecstasy fill you
to the tips of your fingers and toes without cautioning us
to be careful, to be realistic, to remember the limitations
of being human.

It doesn’t interest me if the story you are telling me is true.
I want to know if you can disappoint another to be true to yourself.
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if you can dance with wildness and let the ecstasy fill you
to the tips of your fingers and toes without cautioning us
to be careful, to be realistic, to remember the limitations
of being human.

It doesn’t interest me if the story you are telling me is true.
I want to know if you can disappoint another to be true to yourself.
If you can bear the accusation of betrayal and not betray your own soul.
If you can be faithless and therefore trustworthy.

I want to know if you can see Beauty even when it is not pretty every day.
And if you can source your own life from its presence.

I want to know if you can live with failure, yours and mine
and still stand at the edge of the lake and shout to the silver of the full moon,
“Yes.”

It doesn’t interest me to know where you live or how much money you have. I
want to know if you can get up after the night of grief and despair
weary and bruised to the bone and do what needs to be done
to feed the children.

It doesn’t interest me who you know or how you came to be here.
I want to know if you will stand in the centre of the fire with me and not shrink
back.

It doesn’t interest me where or what or with whom you have studied. I want to
know what sustains you from the inside when all else falls away.

I want to know if you can be alone with yourself and if you truly like
the company you keep in the empty moments.

(Oriah, 1999, pp. 1-2)

I examined the reality of facing my own death and how death has affected how I
and others live our lives. I wanted to write about what I found out in the hopes that it
might serve others. I had no idea where I was going and at times experienced a sense
of being in an altered reality. I did not have a plan for the outcome. I became frightened
as I lost sight of the shore. I stayed with it and in the end I found myself walking along
the shoreline once again. It was the beginning of integration.
Death shows us the ultimate unmasterability of our lives and therefore something of the bogusness of trying to master the lives of others. If I am intractable to myself, I can hardly demand instant pliability from others. Only by not mistreating oneself-by accepting that you have no final dominion over yourself, that you are a stranger to yourself—can your dealings with yourself be a model for your dealings with others. One would not wish to be treated by some people in the way they treat themselves. And this means renouncing the death-dealing ideology of the will. (Eagleton, 2003, p. 213)

As an educator, I wrestle with what we can provide our learners to mitigate the complexities of our world. As I confronted multiple deaths in my life I questioned if knowledge about death is an urgent moral issue for the Deaf and hard-of-hearing community. It certainly was for me. If my personal understanding of death increased, would it benefit other learners? Would it bring answers on how we could live and what could we live for?

The chapters that follow contain my review of the literature, my documentary film and its analysis, my findings and recommendations.
Chapter 2.

Review of the Literature

The roots are Sign Language.  
The trunk is the Deaf community.  
The branches are the various organizations and institutions.  
The leaves are the changes that happen in a living, growing culture.  
(Stokoe, 1978, p. 254)

In Chapter 2, I have begun the review of the literature by defining: what is meant by deafness, the Deaf community, and documenting the history, language and education of the Deaf.  Familiarity with what has occurred in the past may provide a more meaningful and precise understanding of the present day status of deafness and how that identity and ethnicity interfaces with the community at large. It may also serve to illuminate the evolution of current trends and controversies that still burn in our communities. I have attempted to capture significant and pivotal events that have influenced the language and culture of members of the Deaf community you are to about to meet in this dissertation.

The second section of this chapter renders a view of death and dying from a Canadian perspective.  The psychological, social and cultural points of view of death found in the death literature to date have provided important information.  It should be no surprise that the bulk of the death landscape literature found in the fields of medicine, social work, psychology, philosophy and religion through literature, books, articles, organizations and journals concerns and attends to those who can hear.

The process of dying and subsequent death is often hidden because ours is a death-denying society. Kübler-Ross (1975), hailed as a guru in the death movement originating in the late seventies, concludes it this way. Through “acceptance of our finiteness, we can grow; for death provides a key to the meaning of human existence” (Kübler-Ross, 1975, p. 7).
Death and dying relies so much on communication. Do Deaf individuals who confront the death of a loved one, or as they confront their own deaths, have a variety of communication needs that often go unnoticed? Do Deaf and hard-of-hearing individuals experience the death and dying of a loved one differently because of communication issues?

The final section in this literature review includes a short preamble about “story-telling” in the form of arts-based research and filmmaking. I will present the how and why of choosing arts-based research and documentary film methodology to answer the smouldering question: Do Deaf and hard-of-hearing individuals experience the death and dying of a loved one differently because of linguistic, cultural and audiological differences? What are their experiences? We will hear (see) from them first-hand about personal experiences as they faced the dying and death of their loved one.

**Definition of Audiological Deafness**

Generally speaking, deafness may be defined as a complete or severe impairment which is of sufficient severity to make auditory communication difficult or impossible without amplification. It is important to note, that in the literature, there does not seem to be a general consensus as to a universal definition of the term *deafness*. As Schein and Delk point out, “The factors considered in a given definition usually reflect the interests of the particular discipline propounding it. Since there is neither statutory penalty nor benefit for being Deaf, there is no legal definition of deafness” (Schein & Delk, 1974, p. 34).

More specifically, though, hearing loss, as determined by the pure-tone auditory testing method, is classified by the degree of decibel (dB) loss over the speech range of frequencies (250dB-4000dB). Hearing loss is further classified in terms of the severity of the loss. Classification standards vary, but the following breakdown is essentially representative:
Table 1. **Classification of Audiological Hearing Loss Standards**

<table>
<thead>
<tr>
<th>Decibels</th>
<th>Classification</th>
</tr>
</thead>
<tbody>
<tr>
<td>90 dB or greater loss</td>
<td>Profound loss</td>
</tr>
<tr>
<td>70-90 dB loss</td>
<td>Severe loss</td>
</tr>
<tr>
<td>40-70 dB loss</td>
<td>Moderate loss</td>
</tr>
<tr>
<td>25-40 dB loss</td>
<td>Hard-of-hearing</td>
</tr>
<tr>
<td>under 25 dB loss</td>
<td>Normal loss</td>
</tr>
</tbody>
</table>

In the English language there are many terms which are used to describe individuals who suffer from some degree of hearing loss. Terms such as Deaf mute, Deaf and dumb, and hearing impaired are no longer palatable in our contemporary discourse as they imply a narrow pathological view of deafness. Instead, terms that define hearing loss by means of socially acceptable, culturally appropriate and politically neutral definitions are employed here. A few of these terms are Deaf or deaf, hard-of-hearing, Deafened and deaf/blind. To distinguish between those who are audiologically Deaf and those who are culturally Deaf, I use the capital D Deaf to indicate those who use sign language and are part of a linguistic and cultural Deaf community. These terms have been included to familiarize the reader with terminology that will be found throughout this discussion. In the world of hearing loss many of these terms are used interchangeably to define the variety of target groups that I referred to in this work.

**Story-Telling, Discourse, and Film Making**

What's particularly important to appreciate at the onset of this writing is that the very act of communicating through oral means and having the audiological capability of hearing is an act of communication and privilege that most of us take for granted. Our working world is sound-based, our social worlds are sound based and for the most part, information is transmitted through the English language.

Listening and hearing stories through our ears renders the listener captivated through sound. We can hear the details, watch the face for emotion, and we can listen as the sounds tell us the throat is tightening. The quivering in the voice prepares the
listener as warning “bells and whistles” that pain or emotion has surfaced. The person in front of us is in pain. Individuals have the capacity to share very tragic losses that continue to haunt them long after their loved one has gone. *Most often we just don’t give it a second thought*. That is, until you have met someone who is Deaf or hard-of-hearing or deaf/blind.

What makes a good story? According to Maxwell (2004), in *Transcending Invisibility Through the Power of Story*, her grandfather, Deaf, transcended his invisibility (blue collar worker) because Maxwell as school administrator explored the custodian role he played and how he conducted himself as a Deaf person in a support position role amongst all hearing administrators. The out-of-the-ordinary experiences are ingredients for a good story because the “story” is something “interesting” and “reportable”. (Maxwell, 2004)

I would argue with this definition. Story is both universal and unique. Universal in that we can all relate to its archetypal nature of pain, fear, joy, various emotional responses; but the details of the story are unique to the teller and teach us to understand the stranger’s heart.

Deaf and hard-of-hearing life stories about the death of a loved one are not out of the ordinary, because as we will see, they are similar to typical hearing everyday death stories. Communication experiences through the telling, reveal a variety of communication practices that are unique to the teller and do influence the event. Bruner (2001) says:

> The only requirement imposed by having to tell a life story is that one is “interesting.” What makes for something “interesting” is invariably a “theory” or “story” that runs counter to expectancy or produces an outcome counter to expectancy. But expectancy, of course is controlled by the implicit folk psychology that prevails in a culture. It is the case, then, that a story (to meet the criterion of tellability) must violate canonical expectancy, but do so in the folk-psychologically canonical that is itself canonical—that is a breach of convention must itself be conventional. (p. 30)

Labov (1972) refers to this breach of convention as reportability. That is, “an event is not reportable if it is something that happens every day; to be turned into a
story, an event must either be unusual in some way or run counter to expectations or norms” (p. 390).

**Socio-cultural Linguistics of American Sign Language**

The primary focus of the research is on Deaf community members (those who use Sign Language) sharing first-hand through visual means, experiences of the death of a loved one. You will meet one Deaf participant who is facing death herself. In most cases, the cultural and linguistic experience is different with people who are hard-of-hearing. I have included one narrative from a hard-of-hearing participant. Hearing loss of any kind can draw parallels and distinctions on experiences with death depending on the whole person.

Linguistic variables make immense differences on the acquisition of language and influence comprehension and usage of the English language. Were they pre-lingually deaf or post-lingually deaf? Were they educated in a hearing classroom visited by an itinerant teacher or were they educated in a school for the Deaf where sign language was used amongst their peers? When was the onset of the hearing loss diagnosed? Did they receive hearing aids early? Which language is their first language? People have different audiological abilities based on the hearing loss, and this also affects how they hear or if they can lip-read. In some cases, this affects how they process information.

Kannapell’s (1994) discussion on personal identity is disappointingly confined to the *deaf-related* terms that have been used to describe deaf people, and this appears to make the assumption that deaf people always regard deafness as a dominant aspect of their personal identity. I have no doubt that deafness is important, but my experience in counseling deaf people is that the degree of importance or dominance of ‘deaf identity’ is often socially constructed and may vary at different stages in the developmental cycle and under the influence of different environmental stressors. Parallels are often drawn between the experience of Deaf people and that of Black people (Taylor and Meherali 1991) or women (Nowell 1989), but in the latter two groups it is generally accepted that ethnicity and gender at the level of personal identity are integrated and evaluated by the individual in different ways and to different degrees. Because deafness works directly at the interface between self and others in its influence on communication, intimacy, social affiliation, and social
acceptance, the psychosocial conflicts involved in its integration will depend on how the individual manages personal and socio-cultural stressors. In this context, scant or implicit reference is made to the belief and value systems underpinning Deaf or hearing culture or those of other cultures and subcultures of the Deaf community itself. As a result, research shows limited awareness of the use of deaf-related terms as labels and stereotypes which ‘both aid and destroy identity simultaneously’ (Bernard 1992).

(as cited in Corker, 1996, p. 56)

Social and geographical conditions influence a variety of sociolinguistic and cultural frameworks. Social position, class, parental involvement, school choices, hearing loss, educational philosophies, rural or urban living and the availability of audiological services also affect hard-of-hearing individuals’ identity. Each person has a unique blueprint regarding the effects of the hearing loss. Hard-of-hearing individuals are also affected by communication issues surrounding the death of a loved one.

Discussing the death of a loved one can be emotional, painful and vulnerable. Encouraging individuals to tell their stories in their native language allows them to reflect and share naturally. Capturing individual stories in American Sign Language (ASL) was a method employed to increase the ASL participants’ comfort and confidence. Participants could tell their stories in either language, English or ASL. This option allowed them the power of expression without having to think in a second language. I have termed this method “the making of a visual documentary.” This method of visual documentary of Deaf and hard-of-hearing participants implied that each and every participant could transcend her invisibility and remain equal to her hearing peers as she recounted stories of loss.

There is no immediate translation necessary inherent in the interview process. Participants expressed themselves directly and effortlessly. Their experiences and language use in their Native ASL was rich and spontaneous. As a filmmaker, I am interested in the power of film and the visual to move people and to have audiences connect to the participants. The act of viewing visual documentary film engages our senses and engages our subjectivity. I selected documentary filmmaking with this target group as a conscious method to share what needs to be seen. In his book, Film after Jung: Post-Jungian approaches to film theory, Singh (2009) explains the necessity of meaningfulness in the following way.
It is a sensuous act and affective act, connecting . . . the intimacy of perception-expression of our experience of it . . . it is an exploration in meaningfulness-not only what film narratives and images mean, but the human, all too human, experience of finding films meaningful. (p. 177)

This Deaf visual, linguistic and cultural group is “interesting and reportable” in itself. Even more interesting and reportable, is how Deaf people interface with the broader society on issues that affects us all.

Death has and always will be with us. It is an integral part of human existence. And because it is, it has always been a subject of deep concern to all of us. Since the dawn of human kind, the human mind has pondered death, searching for the answer to its mysteries.

(Kübler-Ross, 1975, p. 1)

Deaf individuals live and breathe in rich, distinct culture and linguistic pockets all over the world. This fact sets them apart from the dominant discourse of English, hearing mainstream society.

The history of relations between the society of hearing-speaking people and the community of Deaf-signing people is an excellent case for study in the motives and means at work when diversity leads majorities to oppress minorities.

(Lane, 1984, p. xiii)

The dominant discourse in our academic, institutional and cultural milieus is spoken and written English. Although we interface with a multitude of spoken languages and are blessed with exposure to the riches of other cultures, our governance and business is conducted in written and spoken English. There is great effort to provide access to and deliver services to the diverse spoken minority communities who use either written or spoken English as a second language.

This said, one cannot deny that the majority of our educational and governmental systems and social, legal and medical services are created for dominant mainstream culture. We are a sound-based society with a plethora of opportunities for gathering information and giving out information through our ears and our mouths. Brown (1989) says:

Minority groups all face special problems. Some fare better than others because they have basic means of communication and can respond to
you with the same tools as you: their mouths and their ears. But for us Deafies it is different. We have developed our own means of communicating with ourselves and with the outside world. It is a silent language that allows our hands and our faces to speak like no other language. It should be noted at this point that we Deaf people call ourselves “Deafies” and, although the word cannot be found in Webster’s Dictionary, we are certain that one day it will be. (Brown, 1989, p. 9)

Language and Culture: Deaf Community-Identity

What is meant when we refer to the Deaf community?

If we look at the functions of language—self-exploration, self-expression, social interaction with others and a conveyor of information about the environment, it seems that language must act as a bridge between personal and social identity rather than exist as a distinct identity type. Generally, within the deaf community, language is seen as inextricably linked to social identity as the language or languages that deaf people are able to use or feel comfortable using will often determine the dominant social affiliations that they make. Language is also bound up with demonstrating group loyalty. If we view language as an identity type, we are in effect saying that it is possible, at least in theory, for someone to be Deaf and oral. Though there may well be individuals who would chose to exist in this state of personal identity, it may represent a conflict between their personal identity and their social identifications. They often exist in isolation because they are seen as socially unacceptable. (Corker, 1996, p. 56)

The Deaf community is that group of Deaf and hard-of-hearing individuals who share a common language and culture (Baker & Paden, 1978). The use of ASL is the major identifying characteristic of members of the Deaf community.

American Sign Language (also called ASL or Ameslan) is a visual-gestural language created by deaf people and used by approximately one-half million Deaf Americans and Canadians of all ages. What is meant by *gestural*? The units of American Sign Language are composed of specific movements and shapes of the hands and arms, eyes, face, head and body posture. These movements or gestures, then, serve as the ‘words’ and ‘intonation’ of the language. What is meant by *visual*? Since American Sign Language uses body movements instead of sound, “listeners” or receivers use their eyes instead of their ears to understand what is being said. And because all linguistic information must be
received through the eyes, the language is carefully structured to fit the needs and capabilities of the eyes.  

The term has demographic, linguistic, political, and social implications (Padden, 1980).

Baker and Cokely use the term Deaf community to refer to the Deaf cultural world as well as to an extended unit of people involved in deafness. They suggest that there are four avenues of membership in this extended Deaf community—audiological, linguistic, social and political. The audiological avenue refers to the hearing impairment; the linguistic to the ability to sign; social to interaction with Deaf people; and the political to being involved in the political realm on behalf of deaf people (1980:56).  

(Rutherford, 1993, p. 104)

Figure 2 is useful in describing the relationship of hearing individuals to the Deaf community. If you are hearing and can use ASL or have a connection to the Deaf community (i.e., have an immediate or extended family member who is Deaf), your position is mitigated to some degree. You are not an outsider, and you don't have full membership in the community. Because of the linguistic and social connections to the Deaf community, hearing people are seen as members of the larger extended Deaf community.
It is important to one’s sense of identity—personal or group—to define what one is. But equally important to identity is to define what one is not. Thus far, we have seen illustrations of this with “Deaf” being “not-hearing.” Broadly, the in-group is Deaf/not hearing; the out-group is hearing/not Deaf.

These definitions of in-group and out-group are critical for the maintenance of the minority identity. For Spicer it is this oppositional process that creates what he refers to as “persistent identity systems” (1971:797). This is especially true for a minority group that is not seen as a collective people by the majority, but whose members, rather, are defined by the hearing majority as being isolated individuals with a hearing problem. The majority world controls the institutions that in turn control the education, socialization and enculturation of the majority of Deaf people. Dundes states that “the persecution of minority cultures (for example, Jews, blacks, etc.) by majority cultures has resulted in these oppressed peoples clinging to their identity for dear life….. Moreover, since minorities experience opposition more than majorities, it is perfectly reasonable that minorities have more of a stake in defining identity (especially their own) than do members of majority cultures” (1985: 239). With the added oppression suffered by Deaf people; it is no wonder that there is so much attention paid to the strict maintenance of group boundaries and to the reaffirmation of the Deaf identity. This befuddles
much of the hearing world who “are only trying to help Deaf people” and who don’t understand why there is so much animosity to the hearing world.

Defining Deaf by illustrating the hearing other defines the boundary between the Deaf and hearing worlds. (Rutherford, 1993, pp. 105-106)

Thus, individuals who are deaf but who do not use ASL are not considered members of the cultural group (Baker & Battison, 1980).

Membership in this cultural group is based more on “attitudinal Deafness” than on the actual degree of hearing loss. As Baker and Padden explain, attitudinal Deafness means that individuals have, on the basis of certain characteristics, identified themselves as members of the community and are accepted by the other members (1978). (Rutherford, 1993, p. 1)

Considering how much of our socialization and education depends on language, we cannot understand the culture of Deaf people without understanding the educational system that controls the Deaf individual’s enculturation and linguistic development. To get a true picture of that educational system, we must look at a brief history of its evolution together with the development of ASL.

**History and Early Education**

Over the last several decades an increasing number of scholars and academics have written on Deaf community, culture and linguistics. A meticulous timeline was documented by Susan Rutherford in 1993, when she completed her PhD, *A Study of American Deaf folklore*, which examined how the Deaf community can be studied and better understood both as a cultural group and as an oppressed linguistic minority group through its folklore. It was her dissertation and her ability to use the study of folklore to shed light on a community that has had a rich history and often remains invisible. I have attempted to summarize her documented public history of the education roots of Citizens who are Deaf since the early 1800s. The history of Deaf education can be divided roughly into four periods. While these education periods are often defined by specific events, they do overlap. There was not one method of instruction.
Educational Philosophies of Deaf Children

The follow summary is a heart-warming story about a Protestant minister, Gallaudet, travelling to France in 1817, intent on finding educational strategies to teach Deaf children. It was also the extraordinary relationship between Gallaudet and a remarkable French man living in France, relocating to America to establish the first permanent school for the Deaf in Hartford, Connecticut. This rather unusual coupling of the Rev. Thomas Gallaudet and the Deaf French man, Laurent Clerc, is cited as the pioneers in the development of ASL, as we see today. These two men changed the face of Deaf education in America.

The fact that the American Asylum for the Education of the Deaf and Dumb (now the American School for the Deaf) in Hartford was established as a residential school created a linguistic community of Deaf people communicating in a visual mode. Laurent Clerc had taught French Sign Language (FSL) to Gallaudet, and together they provided linguistic role models for the students. (Lane, 1977, p. 3)

The schools and their staff and students provided the linguistic environment within which the language continued to develop. The importance of this creation of the essential environments for the natural development and establishment of a language cannot be overstated. As Stokoe (1965) has written, “The foundation of the Deaf subculture resulted essentially from two patterns of behaviour: the attendance of Deaf children in residential schools and the use of sign language among the students” (p. 300).

The educational approach that Gallaudet and Clerc used was called the “Combined Method.” The children were schooled in the French Sign Language that the two men brought from France, as well as in speech. “In general, this combined oral and manual method was the standard approach in Deaf education during the 1860s when the ‘Oral Method’ took hold” (Lane, 1977, pp. 3-7).

The Oral Method’s emphasis is on speech only. Sign language is forbidden both in and out of the classroom, since proponents of the Oral Method claim that to allow signing hinders the development of speech in Deaf people. The goal of the Oral Method is to “normalize” Deaf children so they can be like hearing people. In fact, a look at old
Deaf Education texts reveals references to teaching the child to hear. Children who failed at the Oral Method were often thought to be slow or stupid and were sent as a last resort to a Manual or Combined program. It was this shift to the Oral Method that began what some refer to as “The Hundred Years’ War”—The Oral/Manual Controversy (for further discussion see Jacobs, 1989; Lane, 1985, 1992; Mindel & Vernon, 1971; Winefield, 1987).

This shift in educational philosophy occurred at the same time that there was a shift in representation of Deaf people in the educational decision-making process. In the mid-1800s there had been an acceptance of Deaf educators in Deaf education. However, as the shift to oralism took hold, this acceptance of Deaf teachers, and of Deaf administrators being involved in the decision-making process, began to wane. In fact, many of the Deaf schools that had been founded by Deaf people gradually were taken over by hearing administrators (Jacobs, 1989). The rise of the Oral Method brought a decline in self-determination for Deaf people as an impingement of their language by decision-makers outside of the Deaf community and Deaf experience (Jacobs, 1989).

By 1880, an International Conference of Teachers of the Deaf (ICED) held in Milan, Italy, resolved to settle the Oral/Manual conflict. The congress, considering the incontestable superiority of speech over signing in restoring the Deaf mute to society, and in giving him a more perfect knowledge of language, declares that the oral method ought to be preferred to that of signs for the education of the Deaf and dumb.

(Gordon as cite in Rutherford, 1993, p. xvi)

“Notably, there were no Deaf persons involved in drafting the resolution” (Rutherford, 1993, p. 5). It is safe to surmise then, that, 131 years ago, hearing people dominated the decision-making in Deaf education and as such were confronted with the spread of the Oral Method.

Attempts to suppress ASL were numerous and strong. It was hypothesized that if Deaf children were to sign, it would hamper their development of speech and impede their development of English. There are many oral narratives that have been well documented some of which include: Deaf children often had their hands struck with a ruler, put in paper bags, tied to their chair or otherwise immobilized as a punishment for even the most simple of gestures. (Rutherford, 1993, p. 5)
And, those practices were not confined to the 19th Century.

Since sign language is a visual, spatial, and kinaesthetic modality, the communicative, expressive, and lived space of Deafness emphasizes the hands and eye. In order to understand one another, seeing each other is very important. Yet there is a mainstream assumption that to be Deaf is to not be able to hear at all, that such an individual lives in a world of silence. There are many scales of what Deaf individuals can and cannot hear; as a result, it is more useful to think about how Deafness functions as a multi sensorial experience cutting across what the mainstream tends to think of as the registers of hearing and Deafness. (Kochhar-Lindgren, 2006b, p. 418)

According to a large number of Deaf community members in British Columbia, as early as 1922 until 1992, policies and procedures of the government education system included for the most part, students not being able to use sign language in the classroom. Although the educators and administrators had the best intentions at heart, a large percentage of educational curricula and the language of instruction by hearing teachers of the Deaf were often delivered by hearing teachers who could not sign very well, or not at all. They continued to use oral methods which many students could not understand.

There were parallels in the American systems of education for Deaf children. There was no consistency among the educators. Many of the hearing teachers could barely finger-spell their names and they couldn’t read the children’s signs at all. It is easy to send out unintelligible pidgin signs and the children didn’t dare correct the adults. Yet among hearing people, hearing teachers in this situation often claimed they were adept at signing (Walker, 1986, p. 29).

Complicating matters in my mind was the misfortune of students not having ASL communication on a daily basis from parents in the family home. Ninety percent of deaf children are born to hearing parents. They often don’t use sign language well and this creates a complex family dynamic of communication. Deaf children become alienated by language differences and in some cases by residential school. This fact impacts language socialization in the family.

Deaf children have outsider status within the family unit. Because communication is difficult, normal family interactions or discussions would be short, easily
misunderstood or not included in information sharing. Incidental learning in a hearing environment are important ways on how children acquire and make sense of information. One common narrative among Deaf individuals who have hearing parents is that conversations in the home were off limits to them because they couldn’t participate or conversations were often short and answers to their questions were no or yes.

The barriers between hearing parents and deaf children involving sign language communication meant children and parents were not able to explain, expand or provide information and reasons for parental or child decisions. Further, children and parents would be less able to discuss family values, or go over homework and even bond over educational learning or create linguistic bonding.

Many of the students were residential students, who returned home during holidays and summer vacations. Parents were hearing and many did not use sign language. The passing down of family values and traditions was absent and only reinforced their feelings of “otherness” within the family unit. A sense of belonging and connectedness to family was lost.

This meant that children received their information from each other, and if by chance they were connected to the adult Deaf community they received nurturing and role modelling from them. Although we now live in a technological age where information is at our fingertips and we can connect globally by Blackberries, captioning, Internet and email, this was not the case only a decade ago. In this aspect technology has improved the lives of Deaf people because they can access information. There was a barrier to information from radio or TV or chatting amongst neighbours or friends. There, Deafness isolated them from the rest of hearing society. They were dependent on information from those who gave it.

My parents are Deaf. I can hear. And the fact of their Deafness has made all the difference. It has altered the course of their lives, of my life, of their families’ lives. In a way we were outsiders, immigrants in a strange world. With my two younger sisters and parents, it was as if we were clinging together for safety. There were unbreakable bonds between us. Yet there was also unbreakable chasm, for despite my parents’ spirit and their ability to get along, their world is the Deaf, their Deaf culture, their Deaf friends, and their sign language—it is something separate,
something I can never really know, but that I am intimate with.  
(Walker, 1987, p. 1)

It is no surprise that, historically, many of the students did not receive an adequate education. They did not have command of the English language, nor did they fully understand the grammar and syntax of their own language. They also did not develop social skills or life skills necessary to manage the day-to-day demands that young people so desperately need after leaving the safety of the “home.” The result is and accounts for much of the underemployment or lack of it, a certain level of dependency and marginalization, poverty and economic despair that grips segments of the Deaf community. It is amazing to me that despite all the years of fervent suppression of ASL, the language still remains widespread and vital.

In response to what the National Association of the Deaf (NAD) in the U.S. saw as a fearful trend—a kind of linguistic genocide—this organization initiated a film project for the preservation of sign language in 1913. In his presentation titled “The Preservation of the Sign Language,” George W. Veditz, the then president of the NAD, stated:

A new race of pharaohs that knew not Joseph are now taking over the land and many of our American schools. They do not understand signs for they cannot sign. They proclaim that signs are worthless and of no help to the Deaf. Enemies of the sign language, they are enemies of the true welfare of the Deaf. We must, with these various films, protect and pass on our beautiful signs as we nor have them.  
(Rutherford, 1993, p. 6)

The film project continued until 1920, recording some of the more active bearers of the traditions of Deaf people and those whose signing was esteemed as the most eloquent (Rutherford, 1993). Deaf people since that time have been struggling to free themselves from the chains of the decisions of Milan and the reverberating effects on them individually and collectively worldwide.

Brazilian educationalist and influential writer and thinker on education in the late 20th Century, Paulo Freire, author of Pedagogy of Oppressed, Pedagogy of Hope, eloquently respects all positions involving politics and education; however, his views on minorities, education and social justice, resonate deeply, and it appears that the
necessary rebellion he speaks of in Pedagogy of Hope, have been manifested in the lives of the Deaf community over the decades.

I am convinced that the more the so-called minorities accept themselves as such, and close off from one another, the sounder the only real minority-the dominate class-will sleep. All through history, among the many self proclaimed rights of power, power has always arrogated the right, as an intrinsic condition of its very being, to paint the portrait of those who have no power. And the picture the powerful paint of the powerless, to be incarnated by them, obviously will reinforce the power of those who have power, by reason of which they do their portrait painting. The colonized could never have been seen and portrayed by the colonizers as cultivated, capable intelligent persons worthy of their liberty, or for example, as the producers of a language, advances and changes and grows historically and socially. (Freire, 1992/1994, p. 133)

Fast-forward to Education 2010

One hundred and thirty-one years after the historic Milan Decision, while I was in the midst of writing the beginnings of this dissertation, the International Congress on Education of the Deaf (ICED) once again met in the summer of 2010. This time the conference was held far away from Milan, Italy. It was hosted in Vancouver, British Columbia.

Eight hundred delegates from around the world descended on Vancouver, Canada. The impact of this Congress would have momentous meaning to the British Columbia Deaf community (history makers) and perhaps even the worldwide Deaf community because of a single document called “A New Era: Deaf Participation and Collaboration” brought forth by the local Deaf communities (Canadian Association of the Deaf [CAD], 2010).

This document originated with the BC Deaf community and was “signed by four representatives: Claire Anderson on behalf of ICED, Doug Momotuk on behalf of CAD, Markku Jokinen on behalf of the World Federation of the Deaf, and Wayne Sinclair on behalf of the B.C. Deaf community” (CAD, 2010, para. 1).
The effects of the well-documented historical Milan decision resurfaced when the British Columbia Deaf Community brought forward this document to the organizing committee of ICED. In partnership, the International Congress on Education of the Deaf (ICED) Vancouver 2010 Organizing Committee and World Federation of Deaf President and the British Columbia Deaf Community presented a Statement of Principle that after much negotiation and compromise was ratified and made public.

Reaching agreement on the following statement of principle was hard won by all sides, rehashing a painful history that has in the hearts and minds of Deaf people had disastrous effects on the individual and collective lives of Deaf communities worldwide. This process opened a scab that had superficially, temporarily and stubbornly healed over. There was deliberate and committed negotiation by all groups to adopt the statement of principle. Compromise and good will led the process, preventing the sacking of the proposal by the organizing committee and ensuring success for the BC Deaf community (Sinclair, 2010). The guiding Statement of Principle excerpted below sheds light on the importance of the controversy that rages in the Deaf world and among educators for the Deaf.

Globally, many Deaf citizens encounter the general population’s perception of Being Deaf as one of Disability. This “disability mindset” contributes directly towards the exclusion and devaluation of all people who are considered “different” including those who are Deaf. As a result, Deaf citizens in many countries are still hindered and excluded from participation in the larger society. Many are prevented from equal access to decision making, employment opportunities, and quality education. Despite this mindset, Deaf citizens positively contribute to societies that embrace diversity and creativity. They enhance their nations in areas of education, economic activity, politics, arts and literature. For Deaf people, it is an inalienable right to be acknowledged as a linguistic and cultural minority integral to every society. Therefore, all nations are urged to recognize and facilitate participation from all its citizens, including those who are Deaf. (Sinclair, 2010, p. 6)

Freire’s (1970/2006) seminal work in the Pedagogy of Oppressed, vibrates softly in the sweeping history of the education of the Deaf as they journeyed to uncover their “truth.” His beliefs were that the powerless, in the early moments of their historical experience, accepted the sketch the powerful drew of them. They have no other picture of themselves than the one imposed on them. A significant premise in Freire’s work is
the blending of social justice principles and educational reform. It is easy to draw a clear parallel with the defiance movements of the Deaf community regarding the portrait painted by historical hearing educators, to save themselves, as they are not separate from their language and culture. Freire (1970/2006) also articulated his abiding concern for the oppressed by suggesting "one of the signs of nonconformist on the part of the powerless is rebellion against the portraits created of them by the powerful" (p. 136).

*Pedagogy of Hope*, another example and timely writing by Freire (1992/1994), emphasizes that the tasks of the progressive educator, through a serious, correct, political, analysis, is to unveil opportunities for hope, no matter what the obstacles may be. As you will see in the following pages all the parties involved did just that. In partnership, the International Congress on Education of the Deaf (ICED), Vancouver 2010 Organizing Committee and World Federation of Deaf and the British Columbia Deaf Community and Deaf activists; Deaf citizens around the world challenged the portrait and expectations of those who had the power to paint their pictures 100 years ago. Although, 131 years had passed since the Milan decision, they never gave up on uncovering their truth.

In 1880 an international congress was held in Milan to discuss education of the Deaf. At that time, the members passed several resolutions that affected the education and the lives of Deaf people around the world. The resolutions:

- Removed the use of Sign Languages from educational programs for the Deaf around the world;
- Contributed detrimentally to the lives of Deaf citizens around the world;
- Led to the exclusion of Deaf citizens in educational policy and planning in most jurisdictions around the world;
- Prevented Deaf citizens from participation in governmental planning, decision-making, and funding in areas of employment training, retraining and other aspects of career planning;
- Hinder the abilities of Deaf citizens to succeed in various careers and have prevented many of them following their own aspirations; and
- Prevented the opportunity for many Deaf citizens to fully demonstrate their cultural and artistic contributions to the diversity of each nation.

Therefore, we:

- Reject all resolutions passed at the ICED Milan Congress in 1880 that denied the inclusion of sign languages in education programs for Deaf students;
• Acknowledge and sincerely regret the detrimental effects of the Milan conference; and

• call upon all Nations of the world to remember history and ensure that educational programs accept and respect all languages and all forms of communication. (Canadian Association of the Deaf, 2010)

Lou Ann Walker (1987), a hearing daughter of Deaf parents, briefly and fairly explains the polarized binary positions that have dominated Deaf education for the last century: She summarizes:

The oralist's believe belief in speaking and lip-reading without ever signing; and the manualists are pro-signing in American Sign Language (ASL). There is also a camp of compromise . . . those who favour “Total Communication” or signing while speaking in full sentences. The oralists feel that unless Deaf children master English skills, they will be outsiders all their lives. The point is valid, but to leave a child without language for a moment longer than is absolutely necessary seems cruel to me. (p. 29)

I have tried to provide in the preceding pages a snapshot of significant events that cover 131 years of Deaf education history. As a result of their hope, perseverance, rebellion and good will of all parties involved in the education of the Deaf, history was made in the summer of 2010, bringing to life in my mind, a resemblance to Freire’s (1992/1994), Pedagogy of Hope.

It is impossible within a few short pages to capture the cast of characters and ensuing events and subsequent isolation brought on by well-intentioned philosophies and decisions regarding Deaf education. In the past, students have been unintentionally used as pawns to experiment with the educational approaches that aimed to “educate the Deaf.” Although there are some documented cases of success with oralism, the majority of Deaf students who were profoundly Deaf and visual learners did not receive adequate education in a language they could understand, thereby rendering them illiterate in reading and writing. This result has had irrevocable consequences on the quality of life.

Although both sides of the debate have their points, my theoretical position is unshakeable. Fixating or adopting either extreme in my view only isolates individuals, leaving them incapable of developing proficiency in either language and preventing them from developing bicultural or bilingual abilities. Forcing any one particular method of
instruction was detrimental to English language development, the development of critical thinking and problem solving skills, thereby creating a dependency that often is filled with anger and shame. In addition, isolation from families who did not communicate reinforced feelings of inadequacy and unworthiness for Deaf people. The lack of communication within the broader social context and communities added another layer of ‘us against them’ mentality. This contradicts and is counterproductive to an inclusive education philosophy that promises to prepare students to collaborate and co-operate with individuals, the broader community and contribute to the larger society.

The best that can be said for the Deafness is that it’s an invisible handicap. The worst, that it puts adults at the mercy of their hearing children, at the mercy of parents, at almost anyone’s mercy. It can emasculate men and devastate women. It is an impairment of communication. But it’s not just the disfigurement of words and it’s not just broken ears. It’s most often a barrier between person and person. (Walker, 1986, p. 2)

Within the same few pages of this educational history, we also have been graced with a single dramatic event held in Vancouver, British Columbia, 2010, orchestrated by those who had the power and wherewithal to turn the tide, to shift right the wrongs of the past. With the “New Era: Deaf Participation and Collaboration” document (CAD, 2010), optimism and hope is in the air. Education of the Deaf has closed the door on the 100-year war effectively creating dialogue about the two polarized views that have dominated the educational policies. That students have the right to have education in an accessible language seems common sense to me. In partnership, the International Congress on Education of the Deaf (ICED), Vancouver 2010 Organizing Committee, World Federation of Deaf, the British Columbia Deaf Community, Deaf activists, Educators, and Deaf citizens indeed understood that the tasks of the progressive educator, through a serious, correct, political, analysis, were to unveil opportunities for hope.

Lastly, and for all those who have lived through the experience of being denied their language and the denigration of their culture, the meeting of minds and hearts is the first step to healing.

The so-called minorities, for example, need to realize that, when all is said and done, they are the majority. The path to their self acceptance as the majority lies in concentrating on the similarities among themselves,
and not only the differences, and thus creating *unity in diversity*, apart from which, I fail to see how they can improve themselves, or even build themselves a substantial, radical democracy.  

(F Freire, 2009, p. 133)

The above section on the language, culture and history of the Deaf sets the historical, linguistic and cultural stage from which in this next section we will seek a contemporary view of the Deaf and the death experience.

**Western Perspectives on Death**

*Tears*

**Tears! Tears! Tears!**

*In the night, in solitude, tears;*  
*On the white shore dripping, dripping, suck’d in by the sand;*  
*Tears—not a star shining—all dark and desolate;*  
*Moor tears from the eyes of a muffled head:—O who is that ghost?—that form in the dark, with tears?*  
*What shapeless lump is that, bent, crouch’d there on the sand?*  
*Streaming tears—sobbing tears—throes, choked with wild cries;*  
*O storm, embodied, rising, careering, with swift steps along the beach;*  
*O wild and dismal night storm, with wind! O belching and desperate!*  
*O shade, so sedate and decorous by day, with calm countenance and regulated pace;*  
*But away, at night, as you fly, none looking—O then the unloosen’d ocean,*  
*Of tears! tears! tears!*  

(Whitman, 1892, p. 208)

The experience of the Death of a loved one is a profound and personal process for all those involved, whether it is at the bedside, at home or in Hospice. It can be challenging to navigate the muddied territories of family relationships, emotions and needs in a crisis. It strikes at the very core of our humanity as we come face-to-face with our mortality, functioning as time keepers in the broader context of our lives. Death can also be an angry, bullying pugnacity in its force to everyone on the road of life. It pushes hard, more close to us when confronted with the dying and death of someone we love.

One has known of thousands of deaths—the death of someone very close or the death of masses through the atomic bomb, wars—and all the other horrors that that man has perpetuated on human beings in the name of peace and in pursuit of ideologies. So, without any ideology, without any conclusion, one asks: “What is death? What is the thing that dies—that terminates? If there is any ending to everything, there is a new
beginning? If one’s afraid, then one can not possibly find out what this immense thing called death is. (Vardey, 1995, p. 545)

Kübler-Ross (1975) trusted that the reluctance to speak of death within our culture results in death being the least talked about actuality there is. And at the same time the experts suggest that talking about death brings a license to live. Our society is a death-denying society. But death is inevitable and we must face the question of how to deal with it. Why do we treat death as a taboo? What are the sources of our fears? How do we express our grief and accept the death as a person close to us? How do we prepare for our own death?

We are gathered here today because someone we loved very much and respected very much has died suddenly and unexpectedly…. And of course our hearts are broken. We are gathered here today because we want to express our deepest respect and love for Dave’s family. And we want his family to know just how much he meant to each one of us here. We are here to remember that life sometimes is mysterious and that none of us really understands this thing called life and death. But all of us die one day and while we are together here on earth, life is a precious gift that we all cherish.

(The Very Reverend Peter Elliot, personal communication, 9 August 22, 2009)

Death also can be likened to a taxi driver making its way through the streets of Rome. Close, unexpected terror at every turn, yet we are far enough removed and out of sight to ignore it or to escape it within centimetres of our lives. All the while we are listening to death, sounding its ugly horn, loudly repeatedly around us, but then nudging it out of our way, until we no longer can escape its clutches. Eventually we all die. Taxi drivers in Rome are notorious for their near misses with death until they crash.

A wide range of disciplines are concerned with the topic of death. Sometimes there is an overlap between disciplines, this way we are able to examine death from a variety of perspectives. According to Kastenblaum (2000) in The Psychology of Death, the answers to the big questions—how should we understand the nature and meaning of

9 Priest’s sermon at Christ Church Cathedral, Vancouver, British Columbia, Canada.
death?—are available in the form of competing constructions. Death is the end. Death is the beginning. Death is an end and a beginning, a pass-through state. These are the most salient answers that have been offered through the millennia (Kastenblau, 2000, p. 7).

Author and professor of Sociology at Acadia University, Jeanette Auger (2007) invites us to open our eyes wide and examine how Canadian cultures deal with death in her book, *Social Perspectives on Death and Dying*. She articulates rather convincingly that “while death is inevitable happenings in all of our lives, the perspectives that we hold about death are socially constructed” (p. 27).

From one of the early pioneers in the field of death and dying, world renowned leader and authority on death, psychiatrist Elisabeth Kübler-Ross (1975), emphasizes that death is a final stage of growth. *Death: The Final Stage of Growth* reminds us that the one thing we can be sure of and count on is that we will die.

It is reported that on her deathbed, Gertrude Stein spoke: “What is the answer?” when someone questioned her. She thought awhile, rose from the pillow, and said, “What is the question?” What are the questions we need to address? That, already, is a right question, and there are many more (as cited in Hollis, 2003, p. 14).

Martin Heidegger (1962) pointed out, “we are ‘Beings-towards-Death,’ that is, time-bound creatures whose fate is extinction, propelled toward dissolution from birth, dying in every moment” (p. 353).

In *The Rapture of Maturity: A Legacy of Lifelong Learning* by Charles D. Hayes (2004), a case is made for facing these rather large questions because this moves us to higher ground. Not the kind of ground that encourages us to perceive ourselves as superior, instead the sort of ground that enables us to get down on our hands and knees when the calling comes unexpectedly. Eagleton is absolutely key in the next quote because he is getting at what many others, Derrida, Heidegger, and others have written about (as cited in Chinnery, 2009). Death as the ultimate, “Other,” the ultimate unknown and unknowable (Hayes, 2004).

Death shows us the ultimate unmasterability of our lives and therefore something of the bogusness of trying to master the lives of others. If I am
intractable to myself, I can hardly demand instant pliability from others. Only by not mistreating oneself—by accepting that you have no final dominion over yourself, that you are a stranger to yourself—can your dealings with yourself be a model for your dealings with others. One would not wish to be treated by some people in the way they treat themselves. And this means renouncing the death-dealing ideology of the will. (Eagleton, 2003, p. 213)

Death is a socially constructed phenomenon (Auger, 2007). When we see death not as a given, everything dies, but rather as a socially constructed and maintained phenomena we are getting closer to understanding that physical death is an essentially social experience that takes place in two realms of reality: the structural/public and the personal and private. What will we do with the body? (p. 27). Auger examines in detail the death process and exposes the attributes that constitute a death: “death does not just happen, there are processes involved that include behaviours, expectations, beliefs, rituals and a vast array of everyday social practices that constitute a death” (p. 27).

When we or someone we love dies, decisions must be made about disposal. We will decide whether to bury or cremate; whether to embalm and have open caskets or have memorial services, and so on. We enter into another realm of decision making. (Auger, 2007)

To contemplate death and its reverberating elements, the big picture question is “Do we construct death?” Reason and experience rebel against the notion that we construct death. Cultures may differ in a great many ways, but death obviously is death, as real as it can be. What could be blunter, more decisive than the difference between alive and dead? What could be more persuasive than the millennia of evidence that the living must die? And why would we construct such an ominous concept as death, was there not something powerfully convincing that compelled our acknowledgement.

Death is universal. No one is exempt from death, because no one can escape death. People’s reactions to death are as individual as their own lives, but are at the same time, similar in many ways. Despite the fact we all come from varying ethnic or cultural backgrounds, practise different religions, and live in different communities, there is certain universality to death. This in itself brings comfort along with mystery.
Renowned social historian, Philippe Aries, has written extensively on the history of Western attitudes towards death. His most recent work, *The Hour of Our Death* (Aries, 1980), has been hailed as an absolutely magnificent 1,000-year panorama on death. Aries’ analysis emphasizes the view that the whole business of death can be summed up in simple variations of four psychological themes: “the awareness of the individual; the defense of society against untamed nature; belief in an afterlife; and the belief in the existence of evil” (Aries, 1980, p. 63).

Family life provides the experiences and the broader context that shape our personal understandings of dying and death. Much of what we understand and come to expect about dying and death is gained during our formative years. Family members often provide a great deal of support to dying family members and to each other. Much has been made in recent years about the disintegrating family. Although some aspects of family have changed, from the traditional view of family consisting of a married mother and father and one or more children, families are still clearly influential in Canadian family.

Reduced experience with dying and death has made it more difficult for families to develop collective stances, positive role models, and comfortable traditions to help them cope. Smaller nuclear families and increased longevity have tended to reduce the number of deaths that individual Canadians experience. (Northcott & Wilson, 2008, p. 69)

Robert Nisbet’s (1984) contribution in *Death: Current Perspectives* also suggests that the reason for our inability to deal with death in a more integrated way that not only prepares us to live but also to die is because we just don’t have enough direct personal experience with death.

In modern society people are increasingly baffled and psychologically unprepared for the incidence of death among loved ones. It is not that their grief is greater or that the incomprehensibility of death is increased. The bafflement is in considerable part a result of the smaller size of family, which gives greater value to each of its members. But even more it is a result of the decline in significance of the traditional means of ritual completion. Death leaves a kind of moral suspense that is terminated psychologically only with greater and greater difficulty. The social meaning of death has changed.

(Nisbet as cited in Shneidman, 1984, p. 120)
Death has returned to the stage, having outlived an interdiction that lay over it for most of the century in Europe and North America says Heinz (1999) in *The Last Passage*.

As time is the most valuable thing we have, because it is the most irrevocable, the thought of any lost time troubles us whenever we look back. Time lost is time in which we have failed to live a full human life, gain experience, learn, create, enjoy, and suffer; it is time that has not been filled up, but left empty. (Bonhoeffer as cited in Kuhl, 2002, p. 1)

Growing is the human way of living, and death is the final stage in the development of human beings. For life to be valued every day, not simply near to the time of anticipated death, one’s own inevitable death must be faced and accepted. We must allow death to provide a context for our lives, for in it lays the meaning of life and the key to growth.

The social meaning of death means different things to different people. Some of us feel compelled to enter in companionship with the dying, ensuring we have opportunities to do what needs to be done to assist our dying loved ones. Often, though, we are totally ill-prepared for the torrent of unresolved issues that emerge with a fast approaching death sentence.

Some meanings describe various dimensions of death. In contemporary discussions on the topic, these dimensions include the distinction between death and dying, and the all-important distinction between “my death” and “your death” (i.e., all other deaths; the pivotal role played by the denial of death; the ways in which some deaths are more “appropriate” than others; and the sociology of death, specifically, the social inequality. (Shneidman, 1984, p. 6)

Clearly dealing with death encompasses all that we have been in our lives and at the moment we encounter death, whether it be ours or someone else’s, we become changed. It triggers the totality of assumptions about how we have lived our lives and confronts life and death in a way that is often foreign. For those who have experienced repeated loses and death, we don’t become immune; instead, we enter into an ever increasing consciousness about values and beliefs.
By learning from this, we can turn facts into values. By being woven into our lives this way, death can become less daunting, less of a baleful force which is simply out to tear us apart. It is indeed out to tear us apart; but in the process it can intimate to us something on how to live. And this is the kind of behaviour appropriate to a friend.

**Deafness and Death**

I saw evidence that North Americans are thinking about death and dying as they haven’t in a long time. It is a change that is being driven by many factors. Baby boomers are facing the aging of their parents as well as their own mortality. The AIDS epidemic has brought death close and taught us many lessons about providing compassionate care for the dying. And the debate about physician-assisted suicide, which frames end-of-life issues in the narrowest terms, has been heavily covered in the media and has engaged people in the issue (Moyers, 2000) CNN.

Death is so personal:

regardless of theoretical orientation, experts agree that a significant loss results in a natural pattern of grieving that includes a number of psychological processes: responding to the event by emoting or other activities; comprehension and assimilation of the events; adapting to life without the person or loss object; coming to terms of the events and continuing one’s existence as a changed person.

(Zieziula, 1998, p. 189)

I am reminded of Maxine Greene’s (1967), *Existential Encounters for Teachers*, written over 42 years ago. She says:

As teachers we became concerned not with what he knows but with how he comes to know, how the truths of the world and of consciousness are revealed to the “single one...the teacher’s concern must be the way in which each student chooses his relationship with the various situations which arise; for if knowing is conceived as a relationship with a variety of concrete situations, the students will not be likely to take refuge in the propositions of “pure” reason and disembodied intellect…. As seeker, and knower, he will be participant. He will construct orders and define meanings as he chooses to do so, as he acts and challenges his world…. Only as he chooses can he achieve a continuity of identity and continuity of knowing. As a free individual, he must take his choices seriously and commit in the space he discovers between his limitations and his possibilities. If not, he will flounder “in the possible” and the project which
is his selfhood will become abstract and finally meaningless.

(PP. 163-164)

Whether mild or profound, hearing loss directly impacts communication between Deaf and hard-of-hearing people and everyone else in their world for every waking, resting and sleeping moment of the individual’s life. The barrier to communication most evident in North American society, which is based on sound, successful writing and speaking skills, impacts every aspect of an individual’s life, including childhood development, education, marriage, employment, death, and grieving.

Most hearing people cannot begin to imagine how isolated Deaf people feel in a medical setting. For those individuals who rely on American Sign Language (ASL), spoken and written English is a “foreign” language. English is their second language and grammatically it is very different from all other spoken or written languages. For this reason, written English is not always a good communication alternative for hospice staff. In addition, medical words and jargon not only can be confusing but many words simply do not share the same meaning. (It was only in 2002 that a sign for “hospice” was introduced into the language.) Caregivers also must be careful not to assume that hearing family members know ASL or are skilled at interpreting complex information.

(Schmidt & Meyers, N.d., Para. 2)

Because the volunteer and patient share the same language, culture and history, these volunteers often are able to find out information from a patient that the hospice team might miss. The level of comfort and trust with hearing medical staff can vary greatly among Deaf people. This too can result in a reluctance to make simple requests. For example, when one volunteer visited a hospice patient in a nursing home for the first time, she learned that the patient was cold and wanted another blanket and that he would like a TV in his room (he had “nothing to look at but the four walls”). He had not been able to make these needs understood. She was also able to share with the hospice team that the patient was unhappy about his prescribed diet: “If I’m dying anyway, why can’t I eat what I want?”

(Schmidt & Meyers, N.d., Para. 4)

There is an abundance of death-related literature, movies and resources available to hearing people to help them navigate the subject of death, dying and bereavement. Deaf and hard-of-hearing individuals are a unique linguistic and cultural minority community who make their way in the world much differently than hearing people do.
It seems apparent that people construct their sense of who they are from a range of different experiences, and not just from being deaf. People’s identities and self-images are formed by their racial, cultural and gender experiences, from the experiences in their families, and how they understand these, and from what happens to them in their day-to-day existence, and their understanding of why it does. Indeed people’s accounts seem to challenge our notions of ‘being deaf’ and ‘becoming deaf’, especially when we place these in the context of their other experiences. (Moorhead as cited in Corker, 1996, p. 86)

Little attention has been focused on the communication and cultural needs of Deaf and hard-of-hearing individuals and when they face the death of a loved one. Do they come to terms with death in isolation? It would be plausible to suggest that the linguistic and cultural barriers prevent easy access to a hearing world, and as a consequence Deaf people are disadvantaged by systemic marginalization. Certainly, they have reduced accessibility to information and resources. I would argue that resources and materials do not reflect an understanding or appreciation for the particular needs related to language, culture and identity.

Deaf and hard-of-hearing people have struggled with education and often have low English literacy and high unemployment. On average, Deaf adults read English at a 5th grade level. This means that easy access to the extant resources and information concerning diagnosis and death is not accessible. Information available is not in their first language, ASL, and, secondly, often the text-based information is not written in plain English. Navigating the medical systems can be exhausting for the average literate medical knowledge seeker: “the theory of the deaf community development notes the alienation of the majority of deaf children from their own families. The demographics dictate that this group (the 90 percent with hearing parents) constitutes numerical dominance of the deaf community” (Schein, 1989, p. 131). Compound this with communication and cultural barriers and you can imagine the daunting task it would be to obtain basic needs for support in the event of a sudden death. When facing a terminal diagnosis or faced with the sudden death of a loved one, Deaf and hard-of-hearing people must feel blocked on all communication fronts. I would argue that not having access to communication that respects and incorporates cultural values and beliefs increases the possibility that their sense of identity is threatened.
David Moorhead (1995) in his sensitive analysis of the experience of deafness suggests that identity development is organized around two dominant themes, which he calls struggle and challenge.

Running through accounts of deaf people and professionals are stories of their struggle to find and hang on to their sense of who they are, and to be free to retain that sense through the various circumstances in which they move at different times of their lives. This liberty, and the struggle to attain it, derives from people’s wish to control the circumstances in which they move at different times of their lives. This liberty, and the struggle to attain it, derives from people’s wish to control the circumstances of their lives, and their continual challenge to the people institutions, understandings and attitudes that restrict their ability to do this… It seems clear that people who are deaf – and those who work with them or share their lives—struggle continually against the meanings that other impose on their experience, and the way that this separates them from others. They struggle for acknowledgement of the way they see their lives and wish to live them, and aspire to connection with other people, to share and belong.

(cited in Corker, 1996, p. 57)

The uniqueness of grieving among Deaf people can also be viewed as disability itself. Do Deaf people, in their own unique way, grieve the loss of their hearing? And if so, will this loss affect all future losses? How do Deaf and hard-of-hearing people confront the death of a loved one? When confronting their own terminal illness how do they make sense of the process?

Most writings on the subject utilize the Kübler-Ross model (1969) of experiencing loss, more appropriate for dying people than Deaf people. No research has been conducted to date to determine if this model of grieving fits this specific loss. I suspect it does not. People born Deaf or who become Deaf in the early stages of life do not overtly grieve over their loss of hearing. (Zieziula, 1998, p. 192)

Academic Literature

After a comprehensive search of academic literature, this researcher located three publications related to death and Deaf and hard-of-hearing end-of-life issues. There is a dearth of information in an accessible linguistic and culturally-appropriate medium for Deaf and hard-of-hearing individuals who are providing care and facing end of life issues with a loved one.
In Minnesota, the Deaf Hospice Education Project (DHEP) works to improve access by Deaf people to hospice services. In Canada, the Canadian Association of the Deaf work with the Canadian Hospice Palliative Care Association to develop programs to train and provide Deaf support workers for Deaf clients in hospice and palliative care situations. The DHEP acts as a liaison between Deaf patients and hospice services, and between volunteers and hospice services. There is now a Deaf and hearing palliative care team that works with palliative and hospice services in Ottawa (Ottawa-Carleton Deaf and Deaf/Blind Long Term Care Project).

The Ottawa Deaf Community is working towards establishing a culturally appropriate long term care setting for Deaf and Deaf/Blind seniors in the Ottawa-Carleton area.

Since 2008 SLIAO has committed to working with the Deaf community to provide access wherever needed to meetings, training and information about palliative and long term care. As funding for interpreting in these settings is not well established, SLIAO provides the interpreting at reduced, minimal, or no charge to these organizations while at the same time helping them research sustainable sources of funding for future interpreting needs.

(Sign Language Interpreting Associates Ottawa, n.d., paras. 1-2)

There is no such program in Vancouver Canada.10

According to Salladay and San Agustin (1984) in their article "Special Needs of the Deaf Dying Patient," a caregiver unfamiliar with Deafness may impact the care given to a Deaf patient and family.

The Deaf Hospice Education Project, which began in 1999, has tried to address some of these issues by providing opportunities for Deaf people to attend hospice volunteer training programs. In collaboration with Allina Hospice and Palliative Care, in Minnesota, eight Deaf people have completed a hospice volunteer training program and have served as hospice volunteers for Deaf patients in four area hospice programs: Allina, Fairview Home Care & Hospice, Health Partners—Hospice of the Lakes and Hospice of the Twin Cities. These individuals provide an important bridge between a Deaf patient or family member and the hospice team. Because of their expertise and caring, Deaf hospice patients and family members in the metro area now have access to end-of-life care that better meets their needs.
The professional care giver’s ideal goal is not only to alleviate the physical suffering of patients approaching death as much as possible, but to help patients prepare for recognition and acceptance of the realities of their condition so that they can undertake their last task in life with credit and dignity. The communication process that follows the diagnosis of life-threatening illness is laced with emotional stress, both for the patient who must receive and cope with this information and for the physician or family member who must bear the burden of announcing it. Few physicians or other professionals have received the specific training necessary to readily anticipate and meet the specific concerns faced by the deaf, dying patient and his or her family. (p. 257)

Jack D. Gordon, President of the Hospice Foundation of America, writes:

Are we talking about differences in age, gender, ethnic background, religious beliefs, social or economic class, educational background, or any others that come to mind? And how do the overwhelming concerns that accompany dying and bereavement add to these issues?

(as cited in Doka & Davison, 1998, p. ix)

Allen, Meyers, Sullivan and Sullivan (2002) contributed to the deaf-death research in their special article entitled American Sign Language and End–Of –Life Care: Research in the Deaf Community. They employed a Community Based Participatory Process of designing a questionnaire, training and employing Deaf community consultants to administer it to seniors. Unfortunately, the analysis of the data is not completed, therefore unavailable for the purposes of this research. The merit in their information is that they provide valuable information for the study of linguistics of ASL and English in survey design for Deaf seniors. The article falls short in providing accessible concrete information about seniors needs. An interesting finding was that the FACES Pain Rating Scales and the Numeric Pain Rating scales often used to assist health care professionals to assess a patient’s level and type of pain has no bearing on ASL.

I agree with Salliday and San Agustin (1984), Zieziula (1998) and Allen, Meyers, Sullivan and Sullivan (2002). Clearly not being familiar with deafness affects the healthcare for individuals facing death or people who are dealing with the death of a loved one. Additionally, because of dying patient’s health needs and communication, sign language communication would ease the process for all those connected to dying and death. Access to American Sign Language access is clearly the best choice.
Although, I appreciated finding these readings, they did not incorporate the voices of Deaf and hard-of-hearing people directly. The information was general in nature and did not reveal more than a review of the basics of care. The research on death and Deaf is scant yet accessing it allowed the groundwork for this research to build on.

My research intends to go further. I want to know what happens to the individual when they face their death and they face the death of a loved one. I would like to know how they deal with the death of a loved one when we know that 90% of Deaf children are born to hearing parents. How does this affect them and their loved ones as they approach the death of a loved one. The research intends to find out the direct experience of Deaf and hard-of-hearing mourners. Although, I appreciated finding these two readings, they also did not incorporate the voices of Deaf and hard-of-hearing people. Frank R. Ziezula, Professor of Counselling at Gallaudet University, Washington D.C., included a much needed chapter in Living with Grief, (1998), Who We Are and How We Grieve. His chapter entitled; The World of the Deaf Community, addresses some variables that may impact grieving among Deaf and hard-of-hearing mourners.

Profound hearing impairment is considered the most difficult of disabilities today because of its direct impact on daily activities. The general public as well as many professionals, continue to misunderstand the ramifications of hearing impairment and Deafness on the psychological and social lives of people who experience this disability.

(Ziezula, 1998, p.181)

And:

One of the most debated questions among professionals working with Deaf people is whether a psychology of Deafness exists that so impacts the lives of Deaf people who are profoundly Deaf that the disability itself alters the psychosocial development, behaviour, thinking, and feelings of Deaf people and results in lifestyles that are very unlike normal hearing peers.

(Ziezula, 1998, p.188)

Hilde Schlesinger (1978), one of the pioneering researchers of Deaf children, asked: “does the absence of early auditory stimulation, feedback, and communication in itself create a propensity toward a particular adaptive patterns? Or, alternatively, does early profound Deafness elicit particular responses from parents, teachers, siblings, and
peers [friends] that contribute to developmental problems leading to a particular set of cognitive and behavioural deficiencies? (p. 2)

Zieziula (1998) responds to this very question in the following manner:

The answer, like many answers in a complex world, is “yes and no.” It is within this nebulous response that an understanding of how Deafness affects the grieving process can be discerned. (p. 189)

He emphasizes that the psychological research does not show that Deaf people are altered in their psychological development because of their Deafness; however, it does show that Deaf people have similar needs with regards to their need for survival, self-worth, companionship, their fear of death, their striving to understand the meaning of life and their desire for a future legacy.

According to Zieziula (1998), there is evidence that people born with a very severe hearing impairment and the loss of auditory stimulation, causes a very different kind of experience to another’s presence. Those experiences alter in some fashion, all developmental aspects of a person’s life, but most importantly, styles of interaction. Deaf people have been viewed in our society from a medical perspective, which places the focus on hearing deficits that need to be fixed, rather than viewing Deaf people as members of a cultural and linguistic minority community. Because of their audiological differences, grief and end of life issues are compounded. This can be found on the emotional realm and on the linguistic and cultural landscape.

Deaf people communicate not the sensory experience of silence but rather the values of Deaf culture. These include the beauty of Sign Language and its painful oppression, the breakdown of family life when hearing parents cannot communicate in Sign Language, the joys of Deaf bonding and the abuses of audiology when the Deaf difference is treated as deviance (Schertz & Lane, 1999).

All of these factors play into facing end of life stages of a loved one and assisting them to resolve interpersonal relationships and unresolved family issues. Communication then is absolutely essential in helping Deaf individuals to address the long-held feeling of separation and difference among hearing family members, especially at times of crisis and loss.
Much of the interaction of Deaf people is impacted by the negative preconceptions and misunderstandings that so many adults have towards disabled people in general and Deaf people specifically. These interactions can understandably give rise in Deaf people, to feelings of mistrust, anger and scepticism regarding the behaviour of hearing people, and may result in weakened ego development. Some evidence for this last assertion can be found in studies of Deaf children born to Deaf parents, compared to Deaf children born to hearing parents (Lou & Carlson, 1991; Meadow, 1972, 1980). Deaf children born to Deaf parents are more confident, exhibit a greater love of self, accept their Deafness, are assertive in fulfilling their needs, and are simply more happy growing up compared to Deaf children born of hearing parents. (Ziezula, 1998, p.188)

Because hearing loss is primarily a communication disorder, it affects both the individual who has it and those with whom she or he interacts. If the listener is hard-of-hearing or oral Deaf and does not understand what is being said, the person speaking will also experience a communication problem. In the same way, speakers, as well as listeners who are hard-of-hearing, share responsibility for preventing or reducing communication problems related to hearing loss. Individuals who are hard-of-hearing cannot prevent or resolve communication problems by themselves; they often need the cooperation of those with whom they communicate.

One can see how the lack of awareness in end of life practitioners, families, and medical professionals, can lead hard-of-hearing individuals to feel isolated and experience miscommunication and frustration. Communication barriers then are the catalyst for needless suffering for hard-of-hearing individuals interacting with end of life processes.

The purpose of the research is to answer as many questions as possible connected to the experiences among Deaf and hard-of-hearing mourners. The final section of this literature review will focus on arts-based research and documentary filmmaking. Within this section, I examine and give a rationale for the choice of using arts-based research. I maintain it to be a reasonable choice and likely the best choice, to gain insight and direct experience with Deaf and hard-of-hearing mourners. Communication is absolutely key and personal experiences among Deaf and hard-of-
hearing individuals facing the death of a loved one or facing death themselves required a
different kind of format that engendered natural visual language. It is hoped that the
readers are open to the elements and values of documentary movie making, research
that is rendered in an alternative format to evoke or provoke understandings that
traditional research format cannot provide with this target group.

**Theoretical Paradigm of Arts-based Research**

The writing of this section was like looking for a needle in a haystack. How does
arts-based research methodology compete with a traditional methodological research
paradigm that has credibility? How could I, as an artist, researcher and educator, locate
the language, nuance and meaning and reveal a methodology that exposed the values
of arts-based research in logical rationale discourse?

Working at creating art with Deaf and hard-of-hearing individuals is an act of
democratizing and equalizing the playing field. My relationships with people, my
interactions and my own personal outlook is that we live and breathe art, in all aspects of
our lives. I read many journal articles and books from a variety of disciplines, and
explored numerous artistic practices. None of these earlier authors clearly captured the
essence of what I had done, or articulated the process and inquiry of arts-based
research in a way that I could integrate into my research. The lens of my search
zoomed in when I was able to review an article on examining the practices of new
scholars in arts-based educational research.

I had found a publication I had been searching for (Sinner, Leggo, Irwin,
Gouzouasis, & Grauer, 2006) that articulates and documents why I chose arts-based
research to answer questions related to death and communication among Deaf and
hard-of-hearing participants. In this document, many excellent arts-based research
scholars were reviewed. Sinner et al. had purposefully analysed 30 arts-based research
PhD dissertations and their processes and found that they were able to outline the
methodologies that arose from their practices. They highlighted four attributes that
supported arts-based research which were:

1. a commitment to aesthetic and educational practices,
2. inquiry-laden processes,
3. searching for meaning, and
4. interpreting for understanding.

Further, arts-based educational researchers are committed to traditions and practices of social science research, but their unique contributions to research methodologies include their commitment to creative ways to knowing and researching as a journey of transformation. They are seeking to spell out in theory and practice how poetry, drama, fiction, visual art, and performance all contribute to ways of knowing and becoming, to conceptions of epistemology and ontology. Their inquiry grows out of emergent questioning that often takes the inquirer into rhizomatic terrain (Irwin, Beer, Springgay, Grauer, Xiong, & Bickel, 2006). Questions lead to interventions, inquiries, possibilities, and inevitably, situations emerge, unfold and are recognized. Through the generative rhizomatic relational nature of questions and situations, a/r/tography moves in different directions simultaneously yet continues to explore a line of inquiry. In this sense, a/r/tography may be a methodology of situations: situations that constantly teach educators to trouble and address difference while being committed to aesthetic inquiry. (Sinner et al., 2006, p. 1237)

Arts-based research has been a professional practice that I have engaged in throughout my career. Imagine my amusement to learn that what I had been doing for the last 3 decades as a researcher, an educator and a filmmaker was a well-documented academic, scholarly approach to research.

Sinner et al. (2006) found that research inquiries often emerge from professional, educational, and/or personal lives of the researchers. Developing educational curricula with Deaf and hard-of-hearing communities has to be creative. The truth of it is, we are all artists and yearn to fulfill that need to answer lingering questions about life.

Sinner et al. (2006) go on to say that questions of concern documented in the collection are wide-ranging and may be described as encapsulating the researcher’s lingering curiosity of being-in-the-world, with inquiry most frequently centered around general themes of the human condition. Artists are celebrated for their examination of inner and outer worlds and sharing their interpretation and perspectives on society. The arts-based dissertations examined:
self-identity (Renner, 2001, see Figure 4), socio-cultural landscapes (Toulouse, 2001), or embodied experience (Linds, 2002)...love (Lee, 2004); death (Dunlop, 1999); memory (Norman, 1999); suffering (MacPherson, 2000); power (Chapman, 2001); fear (Fisher, 2003); loss (Crook, 2001, see Figure 5); desire (Pryer, 2002); hope (Thompson, 2001); and so forth" (Dissanayake, 2003, p. 15). Although these research inquiries are grounded in theory, such arts-based research is sometimes characterized as ambiguous because of the emotive qualities evident in the questions asked at the outset, which are then expressed as sensorial, emotional, and/or intellectual processes of coming to know throughout the inquiry. Based on this collection, the significance of the research inquiry to the field of education may be explicitly stated or not stated at all. If the significance is not stated, the researcher may intend that the audience create meaning from their own situated perspective. Openness is a cornerstone of strong arts-based research. In this way, arts-based research encourages more dynamic knowledge construction in the academy as the significance is not always bound by the researcher.

(Sinner et al., 2006, p. 1237)

In the 1970s, educational researchers began using the practices of artists and art critics to conduct educational research (for example, Eisner, 1976; Greene, 1975; Grumet, 1978; Vallance, 1977). Arts-based research incorporates the processes, form (or structures), and approaches of creative practices in academic scholarship. Therefore, arts-based research draws from the creative arts to inform and shape social science research in interdisciplinary ways, thus redefining methodological vehicles in the field of education (Sinner et al., 2006).

With the introduction of aesthetics, arts-based forms of educational inquiry were formulated, and by the 1990s had grown to include narrative writing, autobiography, dance and movement, readers theatre, multi-media, hypertext, visual arts, photography, music, poetry, and creative non-fiction (among others).

Arts-based researchers in education contend that the creative arts are a mode of inquiry and representation that provides significant perspectives for making decisions regarding pedagogical theory, policy, and practice.

(Sinner et al., 2006, p. 1227)

Arts-based research design begins by envisioning a research approach, engaging in inquiry (questions emerge over time), selecting sources of information and ideas, and then offering interpretations with "intellectual openness and creativity" within practice, in essence, portraying new
understandings textually, visually, and/or performatively.

(Finley, 2003, p. 283)

Kanta Kochhar-Lindgren (2006a), a performance artist and scholar, teaches at the University of Washington, Bothell, in the Interdisciplinary Arts and Sciences Program. Her book, *Hearing Difference: The Third Ear in Experimental, Deaf, and Multicultural Theatre*, investigates performance and Deafness. She is also lead editor of *Exquisite Corpse* (Kochhar-Lindgren, Schneiderman, & Denlinger, 2009). She summarizes the cultural narratives and identities of these communities and she writes about the irregularity of navigating three cultures:

It is important to note, as well, that much of the discussion about how and under what conditions there can be epistemological and cultural crossover between the hearing and the Deaf often downplays, or omits altogether, the discussion of the hard-of-hearing. While it is the case that some hard-of-hearing individuals consider themselves as hearing but wear an aid, there are others who are not hearing and also not Deaf. It is useful to consider the notion of a “third space” as a way of articulating a site where the hearing, Deaf, and hard-of-hearing come together. Much scholarly and artistic work already attests to the ways in which ethnic, racial, gender, and class identities are marginalized as well as recuperated through various manoeuvres to build and stage counter narratives. (Kochhar-Lindgren, 2006a, p. 417)

Most importantly, this work also grapples with epistemological issues about the audist bias built into cultural notions concerning the five senses, voice, and the normal body (issues which have implications for both the Deaf and the hearing). Davis and Bauman, in particular, have made explicit pleas for the extension of Deaf studies into the areas of art and multiculturalism. Simply put, Deafness, as these critics have shown and begun to redress, is under theorized because it is generally eclipsed by the framing of sound practices from an audist standpoint.

(Kochhar-Lindgren, 2006a, p. 417)

Kochhar-Lindgren is key in her perceptions of how Deaf or deaf and hard-of-hearing individuals’ use of language is complimentary to arts-based research and further how disability aesthetics plays an important perspective in the arts:

In contrast, the communicative mode of the hearing person is primarily sound based, and this cultural history became intensified with the advent of the technologies of sound recording, which often rely on an internally focused style of listening. The social construction of Deafness and
hearing as identity categories, systems of meaning, and modes of being in the world also implies the social construction of sensorial experiences. Rather than argue that these modalities are incommensurate with each other, which simply re inscribes a hearing / Deaf binary into our thinking, she argues for ways in which we can, with greater degrees of discernment, imagine more supple forms of cross-cultural encounter and understanding. (Kochhar-Lindgren, 2006a, p. 418)

Arts-based educational researchers are always seeking to understand the parameters of ‘good art’ and ‘good research,’ and they are never satisfied with any checklist, template, or formula. Instead, each new arts-based educational research project is informed by past projects, but is always also seeking to extend the possibilities of what constitutes both research and art. This process is creative and emergent, a dynamic process of inquiry. (Sinner et al., 2006, p. 1229)

**Pedagogical Connections**

The cornerstone of my practice as an artist, educator, and researcher, through this dissertation, film-making has proven to be a credible research methodology when combined with elements of social science research. Incorporating Sinner et al.’s four elements, the act of film-making becomes a commitment to aesthetics and education. In every creative process, you are both learner and teacher, teacher and learner. Who you are when you go in, is not who you are when you come out. It is the journey that is paramount, not the destination. The creative process required holding steady the tensions of all the elements—and the process was transformative.

I yearn for conversations about people’s passions, their complicated and messy relationships, their dreams. Even the lost ones. I want to know what they live for, when and how they’ve encountered death. And how they chose to live. I want to know their struggles and their moments of celebrated triumph. (Crowe as cited in Weibe, 2002, p. 128)

Within a multi-media framework, I created curriculums with diverse groups of Deaf youth and Deaf adults, who possessed a range of communication styles. Deaf community members engaged in diverse topics and community organizations supported the arts-based enquiry of developing appropriate educational resources. In many ways, multi-media seemed the obvious teaching and learning choice as the communities of collaborators were visual language learners and adept at using creative processes that were transformative. The visual media developed reflected the varied needs of the
learners, not only in the educational domain, but also in the personal and collective experiences of community. Community educational collaborations were the foundations and strength of the research as each new project addressed contemporary issues. From the initial idea to the final distribution of visual resources (video educational dramas with accompanying user’s guides), Deaf and hard-of-hearing individuals were central to the process and the development of the line of inquiry.

I want research that begins in a place of unknowing, with a leap of faith, a courageous willingness to embark on a journey. I want research that seeks out mysteries and acknowledges even the muddled, mad, mesmerizing miasma that rises up as a kind of breath and breathing, connected with the pulsing and compelling rhythms of the heart.

(Leggo as cited in Weibe, 2001, p. 180)

[the researcher] would be one of those who dare to handle paradoxes and use them wisely, who dare to combine and create, and who dare to treat methodology as methodology, which sometimes means treating it as more than methodology.

(Weber as cited in Weibe, 2001, p. 198)

In previous productions, Deaf and hard-of-hearing individuals held key roles in all video productions: key technical production crews, writers, editors, directors, and Deaf and hearing actors. My role as producer and writer allowed me to assemble the teams and encourage the video projects in such a way that Deaf and hard-of-hearing community members owned the production. In essence, it was theirs—that is, made by and for the Deaf and hard-of-hearing communities became my motto. There was a sense of accomplishment, teamwork and pride. Together, we engaged in a process of discovery, which often required cross cultural awareness, give-and-take and patience on everyone’s part. This in itself merited successful results.

Penberg’s (1998) dissertation functioned on two levels, as a multimedia presentation that incorporated hypertext, still and video images, and sound on a CD-Rom, and as an arts-based representation of the educational experiences of urban youth engaging in the arts. Penberg’s dissertation creatively used the resources of multi-media to produce what he called an “abecedarian” of educational experiences. His dissertation is an innovative documentary that capitalized on his long artistic and professional commitment to video production.

(Sinner et al., 2006, pp. 1230)
For the purposes of this dissertation, I needed to use a new creative process to answer questions about death and its implications for Deaf and hard-of-hearing caregivers. I also wanted to develop my learning as a researcher and artist. I was passionate about video-making and in keeping with the visual-media framework, “the documentary film medium” as a process of discovery fit well. Having never made a documentary before, the challenge seemed authentic. I was stretching as a filmmaker and researcher and so would the participants as they shared honestly about their experiences. It was about questioning, looking for meaning and interpretation. As a seasoned videographer, the prospect ahead lay in the newness of making a documentary, challenging myself as an artist, researcher and educator to balance competing processes and engage in a new creative process complete with the requisite ticket to the mystery of the unknown. We were all going on an adventure.

All Arts-informed research accounts are written, performed, or revealed with the express purpose of connecting, in an holistic way with the hearts, souls, and minds of audiences. They are intended to have an evocative quality and a high level of resonance for audiences of all kind.

(Cole as cited in Weibe, 2001, p.216)

This timely and difficult topic arose both from the researcher’s own personal journey of multiple deaths in a short time and as an arts-based representation of the collective experiences of the Deaf and hard-of-hearing communities confronting death.

Engaging in arts-based educational research often means that researchers are immersed in a journey of discovery, of learning about themselves as well as learning about themselves in relationships to others. In much of the arts-based educational research, there is no simple distinguishing between the researcher and the research. In effect, there is an organic and lively relationship where the researcher and the research are part of an intricate dance that is always evolving. In other words, arts-based educational research is a creative process that is tentative and frequently tension-filled, but often transformative and tensile.

(Sinner et al., 2006, p. 1242)

The next chapter will discuss the making of the documentary; highlight some of the key events that shaped the creative process and the making of the documentary. The reader will meet the participants who journeyed through the process and as Sinner et al. (2006) suggest based on their examination of 30 arts-based dissertations:
This research inquiry is grounded in theory, this arts-based research is sometimes characterized as ambiguous because of the emotive qualities evident in the questions asked at the outset, which are then expressed as sensorial, emotional, and/or intellectual processes of coming to know throughout the inquiry. The significance of the research inquiry to the field of education may be explicitly stated or not stated at all. If the significance is not stated, the researcher may intend that the audience create meaning from their own situated perspective. Openness is a cornerstone of strong arts-based research. In this way, arts-based research encourages more dynamic knowledge construction in the academy as the significance is not always bound by the researcher.

(Sinner et al., 2006, p. 1238)
Chapter 3.

The Making of a *Visual* Documentary

If we knew what it was we were doing, it would not be called research, would it? (Einstein, n.d.)

This chapter discusses some of the choices, challenges and successes we experienced while making the “visual documentary.” My experience with film making was and continues to be about community, ownership and power. This visual documentary process was a different artistic challenge. I located the starting place for the line of enquiry with the phrase “Knowledge is power.” Gaining knowledge is the bedrock of education, where knowledge is sought, discovered, and shared through the interaction between teachers and learners. Creative artistic processes with this target group generally, and definitely for this death research, involved sharing knowledge and power with Deaf and hard-of-hearing community members.

Although I had had experience making educational dramatic films with the Deaf and hard-of-hearing communities, doing research by engaging filmmaking as the line of enquiry was a new challenge. In this case, I had no direct experience with making a “visual documentary film.” Learning and teaching are synonymous with give and take, back and forth; it is a unique process that is fluid. However, knowledge as one obtains it in Canadian society is of crucial significance simply because it is largely constructed within the principle of accessibility to information. Deaf and hard-of-hearing individuals do not have easy access to information.

There is an inherent power imbalance between those with hearing and those without for all the reasons discussed in the first two chapters; varied English literacy, lack of a top-notch education, systemic marginalization, underemployment, and barriers to information. How can there not be? Even with my use of ASL or the use of Sign Language Interpreters, Deaf and hard-of-hearing individuals are dependent on the skill
and language usage of the user to gain access and meaning. As a hearing person, my audiological status often means that Deaf and hard-of-hearing community members are at a disadvantage. Because I can hear, I have access to information and benefit from incidental conversation and a plethora sound-based information. Deaf and hard-of-hearing people are often dependent on information being provided, therefore, as a hearing person, I have more power.

Prepared with this knowledge and an equally open vulnerable heart, I set out to make a documentary about this difficult topic. However there is a difference between making an educational video drama and an educational documentary film. In the genre of educational video drama, dramas begin with fictionalized storylines, which solidify the educational content; a needs assessment often determines the content and method of plot; and the educational components and messaging are created and interlaced with light-hearted drama of culturally appropriate themes. For example in previous films I wrote and produced, English scripts were written and then translated into ASL; key production and all creative roles were filled by Deaf or hard-of-hearing community members; the script was a guideline and the process functioned with a planned storyboard. The videos were made with, for and by the Deaf and hard-of-hearing community. However in the creation of a documentary, there isn’t a storyboard and, in this particular visual project; there was only a question about how Deaf and hard-of-hearing people dealt with the death of loved ones or how they faced their own deaths.

Recruitment

Though I was venturing into uncharted territory as an arts-based researcher by making a documentary, getting started was not difficult. It began with a desire to find people willing to share their stories, and my yearning to listen with my eyes from those most often unseen. This undertaking has come full circle. Years ago as a young aspiring writer, I was puzzled and wondered how Deaf and hard-of-hearing people could express themselves and be heard when so few people could communicate in sign language. In my naivety, I wanted to write their stories. I surmise now, there was an affinity and compassion that was established early on. I bonded to their experience of being silenced. I realize after 30 years, I was familiar with being silenced during my
childhood and teenage years. Writing and reading became both an escape and a viable avenue for expression.

Learning the language, culture and traditions permitted me access to the people. As a recipient of thousands of communications and stories over the years by Deaf and hard-of-hearing people, I equate the experience to a “live performance.” Deaf people are natural story-tellers, often animated, expressive and entertaining as they tell a story in sign language. Deaf storytelling is a method of performance encompassing many functions such as acting, teaching, sharing information, embracing and partaking in cultural traditions. In order to tell their stories, I needed the storytellers. Humour is a cultural tradition and the linguistics of ASL provides a natural forte into comedy stage performance. This was a different kind of story. We could be venturing into painful memories connected to death, touching on unresolved grief, frustrations and disappointments.

Death is central to our lives and as such can become a great teacher. So what can the death of a loved one teach us? What could Deaf and hard-of-hearing people teach us (and me) about their experience with death? What were the good, the bad and the particular tensions that would be revealed? Did they experience such a thing as a good death?

When my parents were dying, I vividly remember wanting time to stop as though I could stop the inevitable, I wanted to do what was right for Dad and Mom; I wanted to do what was right for our family. Sitting with both of my parents during their final days and moments of life were two of the most significant experiences I have ever known. They were also some of the most painful and angst producing moments of my life. The process of care giving as my parents lay dying was difficult. The death of my parents, friends and community members led me to question the meaning of my life and those who are affected by the death of the loved one. I wasn’t prepared for the actuality of the experience of death. For the participants and me, it would be a collective experience of a voyage together along the corridor of the unknown.

The course of action was dependent on all the players, which fuelled the creative process. In this instance, I was in a disadvantaged position. I worked throughout the
visual documentary process in ASL, which is my second language. I was “outsider” and at times, at their mercy: their graciousness, generosity of time, participation, acceptance of the creative process and patience with my language abilities were poignant. Neither they nor I had a blueprint for how it was to materialize. This shifted the balance of power, if only temporarily. It isn’t always easy to be in the power position because of one’s audiological status, especially if one is conscious of it. At last, the tables were turned. I was “flying by the seat of my pants.” Venturing into the unknown, I was filled with trepidation and required a certain commitment and trust.

As a researcher, artist and educator, my first consideration was to the individuals who had lost a loved one or were facing death themselves. As a fellow sojourner, I was mindful that the particulars of the death of a loved one would cause pain and suffering. Duly aware that opportunities for dialogue in their own language could also bring on unresolved and subsequent grief, recruitment methods were made from direct conversations and communication with individuals who had shared the loss of a loved one. All recruitment methods were made through community connections. The Deaf and hard-of-hearing community is involved in constant information sharing among members in person, at local events and throughout the community. Individuals who were either facing the loss or who had lost a loved one often shared information about their experience and loss. It was at those chance meetings that participant names and contact details were documented.

The email addresses were available to the general public and were considered to be public domain. Individuals were contacted either in person or email. In a follow-up connection, Deaf and hard-of-hearing community members were asked whether they would be interested in voluntarily participating in the “visual documentary project.” In person or in the email the participants were told that the minimum age necessary to participate was 19 years old.

Electronic technology was also a method of communication that proved very reliable. Social media plays an important role in the lives of Deaf and hard hearing individuals. It wasn’t so long ago, that the only way Deaf and hard-of-hearing people could connect was in person, and as such, social media technology has improved the accessibility to one another and the larger world. The project used email, Facebook, and
instant messaging to contact potential participants who had indicated interest. The emails also asked them to agree to participate in a video-taped disclosure on the death of their loved one. All participants who agreed to take part in the documentary agreed to disclose their identities for the purposes of the visual documentary and were told the reasons for participating in the documentary.

**Conducting the Interviews**

The death of a loved one is a universal experience. I specifically wanted to locate the experiences of Deaf and hard-of-hearing individuals as they confronted death. How do they face the death of someone they love or even their own impending death? How do they communicate their needs through use of Sign Language? Were their differences between how they coped and faced their own death or the death of a loved one? How did they communicate their needs and have opportunities for healing and closure? How did they interface and participate with families, the health care system and hospice or palliative services?

For life to be valued every day, not simply near to the time of anticipated death, one’s own inevitable death must be faced and accepted. We must allow death to provide a context for our lives, for in it lay the meaning of life and the key to growth. (Kübler-Ross, 1975, p.13)

What if you were told you had a limited time to live? Would it change the way you’re presently conducting your life? Are there things you would feel an urgency to do before you died? Are you afraid of dying? Of death? Can you identify the source of your fears? Consider the death of someone you love. What would you talk about to a loved one who was dying? (Kübler-Ross, 1975, p.14)

Preparing individuals for personal disclosure also included discussing the possibility that sharing their experiences may touch on painful memories of grief and loss and as a result may uncover unresolved grief (see Appendix A). We assured them that connections and referrals will be made to local grief organizations for any individuals who needed support. Confidentiality of the individual was maintained by personally contacting individuals to arrange a private confidential interview. All material obtained from the video-taping was kept in a locked cabinet in a locked office.
Interviews were conducted in a private room or location agreed upon by the participant. The objective was to create a safe comfortable zone where they could be themselves and feel at “home.” Several participants requested that the documentary filmmakers come to their homes.

Greene (1988) wrote on educational pedagogy in *Dialect of Freedom*. She argues that people are never alone but always stand in relation to others. Greene drew attention to the importance of community:

> Human beings define themselves through the projects with which they become involved:….By means of engagement with a project, the attitude of wide-awakeness develops and contributes to the choice of actions that lead to self-formation. Greene, who identifies strongly with existentialist philosophy, used one of the centre existentialist terms, *project*, to refer to the intentialized vision of purpose, of making or constructing the self and the world. (Pinar, 1998, p. 100)

Making the objective and subjective room for participants to disclose in their Native Language as they reflected on personal thoughts, feelings and events was paramount. For the participants, being part of a community process confronting issues of death was the right thing to do. I felt good about the possibility that in telling, healing could occur and their contributions to the video could cause positive change.

My vision was to create a climate of confidence, openness and comfort that respected the pace and rhythm of all the participants. It included attending to the participant by using active listening skills (“my eyes” with signing participants and “my ears” with hard-of-hearing participants) and noting and responding to various non-verbal behaviours. I was using a participant-centered approach, establishing rapport and respect.

Using this approach yielded a rich and authentic rendering of their experiences complete with nuance and feelings. The participants shared naturally in their own language and I responded to them in their language. Capturing individual stories in ASL was a method that clearly increased the participants’ comfort and confidence. Participants could tell their stories in whatever method, using whatever modes of communication they chose. Gifted with lifelong friendships and mentoring by Deaf and
hard-of-hearing community members afforded me the luxury of communicating effectively in both ASL and English.

This option, in my mind, legitimatized their power of expression without having to think and express in a second language. I termed this method “the making of a visual documentary.” This method of “visual documentary” with Deaf and hard-of-hearing participants made explicit that each and every participant could transcend her invisibility and remain equal to her hearing peers as she recounted stories of loss. Further, the audience could receptively understand the complexities of the language and not interrupt the process. There was no immediate translation necessary inherent in the interview process.

Whenever significant numbers of Deaf people come together, Deaf communities have come into existence. Sign languages are natural languages that have evolved within the Deaf communities and, as such, are neither universal, nor based upon the spoken languages of their countries. American Sign Language has a grammar and vocabulary distinct from English, just as Japanese Sign language is distinct from spoken Japanese. (Gallaudet University, 2007, p.7)

Capturing the Interviews

In many ways, I welcomed the opportunity to “see it” from their side. A true collaboration with individual community members was created. What followed was the making of the documentary with cultural and linguistic norms and traditions of the target groups. Capturing video-tape narratives in sign language was used as a method to increase comfort for participants to share death experiences in their natural language. Although camera equipment can be invasive and interrupt the intimacy of the disclosure, this did not happen. Once filming was underway, participants became lost in their own narrative and became trancelike in their narratives. In this context, I was a filmmaker, looking through the lens as an observer. At the same time, because of the subject and the sensitive nature of the narratives, I was “listening and attending.” I was immersed in the emotional narrative as well as the line of enquiry aware of the creative process.

It was an organic creative process that began with an idea and the participants shaped the rhythm and flow. This included how the raw footage was obtained, through
various shoots in sometimes quirky locations. Filming graveyard scenes or funerals elicited more than the occasional shaking of the head. Try to imagine the scene. A camera attached to a tripod, stationed inside a small van, with the back open, cameras rolling aimlessly through cemeteries in the midst of daylight. Suddenly, the van would halt and the crew would jump out and capture this or that video footage. The whole documentary with the exception of the scheduled interviews was created through spontaneous collaboration.

As individuals shared their personal stories (narratives of personal death experiences shedding light on what was hard and what worked for them and what was needed to assist them with their process) I knew research had meaning for me, but more importantly it could also have meaning for others. “Dying is as much a matter of the psychological and spiritual as it is of the physical. It involves the whole person—body, mind and spirit” (Hospice Nurse, Nan St. Eloi, 2011, participant in documentary).

Participants expressed themselves directly and spontaneously. As a filmmaker, I am interested in the power of film and the visual to move people and to have audiences connect to the participants. I selected documentary filmmaking with this target group as a conscious method to share what needs to be “seen.” The act of viewing visual documentary film engages our senses and engages our subjectivity.

It is a sensuous act and affective act, connecting . . . the intimacy of perception-expression of our experience of it . . . it is an exploration in meaningfulness—not only what film narratives and images mean, but the human, all too human, experience of finding films meaningful.  
(Singh, 2009, p. 177)

Scholl, 1984, argues that from the perspectives of the humanities and arts, the central issues are the meaning of death in human existence and the effect exerted upon our personal and collective lives by consciousness of death. She refers to the humanities and the arts as a comparison to other disciplines because she argues that the humanities do not aim for some ultimate physical or philosophical solution, for a cure for or postponement of death. Their aim, she explains, is not the dissemination of accurate data and skill, laudable as that may be. The humanities invite individual participation in vicarious experiences with death so that we are able to appropriate such confrontations as our own. Death becomes a friend.  
(Scholl, 1984, p. 8)
As they recounted their confrontations with death, time stood still and our surroundings evaporated as our eyes and hearts locked in conversation. Against all probability, through language and cultural differences and a multi-layered meaning of value and significance, together, we created the process and it carried forward. Some advocate the role of contemporary artists as being that of catalysts for positive social change (Morin as cited in Townsend, 2003). “When artwork is specifically about and/or involves a group of oppressed people or a minority it can be empowering” even though it wasn’t intended (Morin as cited in Townsend, 2003, p. 4).

Preparing the Documentary

Trusting the process turned out to be my daily mantra. It was the participants’ and community members’ process that influenced the filmmaking from beginning to end. Without the collective desire and commitment there would have been no visual documentary. We all trusted the process. The relationship of the filmmaker to the material is central when discussing the role of documentary-film maker and whether or not documentaries can ever be objective. The intention in this process was to be objective as possible in all areas related to the line of enquiry. However, juggling the competing complexities of the subject matter on death, documentary filmmaking and ensuing technical challenges and the linguistic and cultural essentials of Deaf and hard-of-hearing people necessitated a loose partnership between distant observer and active creator.

The relationship of the researcher to the participant’s is important. The Deaf and hard-of-hearing community is small. As a hearing educator for the last 3 decades most of the participants would be familiar with the researcher. The participants in this research were volunteers. I would categorize our relationship as one of professional acquaintance with warm regard. In some cases I may have had more or less connection over the years, depending on the participant. However, I do stand on the periphery as a hearing member, of all those I come in contact with through the Deaf and hard-of-hearing community. The researcher’s use of American Sign Language, understanding of Deaf culture, career history and awareness of the political situation for the community undoubtedly provided a thin layer of entry. However, Deaf and hard-of-hearing
participants chose to participate because they wanted to share their stories and hoped that by doing so they could heal. Did my knowing the participants contribute to the depth of sharing? Yes and no. I believe that the depth of sharing was not so much to do with knowing them, but rather it was the common experience of bonding through grief. I had experienced “death” myself. The researcher had faced the death of a loved one and was interested in finding out about their experiences. The fact that we were sojourners on the journey permitted them to share honestly and deeply.

Participants in this research provided themselves the opportunity of developing a unique working relationship with narrative storytelling surrounding grief. As a peripheral hearing member of the Deaf community I have interacted with most of participants in a collegial fashion on a variety of matters relating to communication access, education, interpreting, or employment. Not all participants were previously known to the researcher. Did my previous connection influence the process? I suspect that the answer to this would be yes and no. Yes because it influenced my approach. The researcher was able to explain the research, its purpose and goals directly with each person in their own language. The research was not based on ideas or papers based on theories, nor on stats from a book; this was relational research. One to one interaction about a very difficult subject made it safe.

The researcher was unique precisely because of the history, knowledge and ability to communicate and listen without having to interpret or go through a third person made the process more intimate and real. The research approach was to treat each participant involved in the research in the same way, and at the same time attend to the unique needs of the participants. There were no predictable outcomes.

The interview process for the researcher was conducted the same for each participant. Each situation was different in texture. The emotional responses, locations and or content from the participants were unique. Death interviewing research seemed to evoke a whole set of emotions or processes that are known only to those who have gone through the death experience.

Was the researcher’s objectivity compromised? The researcher did not have a preset question/answer format. The intent was not to get answers because frankly I
didn’t know what they were. The goal of each interview was to seek their “Truth” regarding their experiences with the death of a loved one. The objectivity was to record them whilst they told their stories. The methods of capturing data were objective in the sense that the researcher was not leading them to any specific answer. There was no answer that the researcher was seeking. How do I define objectivity in relation to capturing data with participants that were familiar? I suggest that the fact that the interviewee had some familiarity with the researcher put additional pressure on the researcher not the participants.

Those who knew the researcher and knew the purpose of the research and had a shared common experience of death with the researcher engendered a trusting interview. The subjective experience for all would have been a positive factor. One participant didn’t know the researcher.

There was a camera person at each interview. They were selected for their skill level and because of their interest in the topic. They volunteered for the filming. All of the signing Deaf participants were interviewed with the researcher (bicultural and bilingual) and a Deaf camera person whose native language is American Sign Language. The deaf /oral participant who used her voice to share her narrative was filmed by a hearing camera operator and was interviewed by the researcher. Clearly, having the appropriate camera person for each interview ensured an easy flow whilst also providing comfort and ease of communication.

In the post-production phase, Karen Foot, a Deaf editor, worked alongside the researcher editing the film for more than a year. Our roles were clearly defined. She wanted to focus her contribution on the technical aspects of cutting the film. The edits were chosen by the researcher and each edit was discussed. Interpretation of the findings was completed by the researcher. However, throughout the process Karen was relied on for linguistic and cultural verification. As a second language user of ASL, the gift of collaboration with a Deaf colleague, clarified and sharpened my lens. Her contributions to the making of the documentary were immeasurable. Paul Lang, a hearing videographer who had previous experience teaching film to Deaf community members provided post production expertise at critical times. He also assisted the researcher to find appropriate sound for the documentary. Captioning was completed by
the core members of video team. Paul and I edited and finalized all captioning for the documentary. Each voice actor was specifically chosen to match a participant. They were given a completed script of their assigned participant narrative and voice directed in a sound studio by the researcher.

Decisions had to be made at every turn. This shaped and created the documentary form which birthed an aesthetic that was specific to Deaf and hard-of-hearing people. My own artistic contributions, camera footage, style and format created a linear, orderly rendering of what took place. The creative process permitted unique exploration of a variety of technical methods for making the film. In other words, I had to put the pieces of a puzzle together and this necessitated hundreds and hundreds of choices about what I wanted it to look like, how it could work, and what to include or not.

The participant narratives were the starting point and remained the focal point throughout. There were some technical details that had to be prioritized. Accessibility came first and resulted in forsaking some creative elements. For example: some camera limitations affected the style of shooting. Seeing the Deaf person on screen while she uses Sign language was vital. This created a smaller choice of camera shots. For example; head shots or extreme close-ups were not possible with the signing Deaf participants because communication is with their hands.

After the documentary was assembled, a second documentary had to be made. This time it was a voice documentary, adding sound, or taking sound away. A voice-over shoot in a studio was organized to make the documentary accessible to hard-of-hearing and hearing people. Captioning was used to make the process more accessible to Deaf and hard-of-hearing audiences. Each of these technical processes were detailed and demanded accuracy and effort. After the necessities for accessibility for potential audience and participants were configured, the remaining footage, style, process and design were constructed around the narratives.

I experienced a certain kind of reverence and astonishment when I watched and listened to people’s pain and sorrow after they had lost a loved one. In the post production stage, reviewing tape after tape, editing and cutting the footage was intense.
And yet, for the purposes of this dissertation, the essence of the participants’
communication experiences was portrayed in approximately 35 minutes.

Faith and trust would have the film emerge on its own terms in an organized,
viewable, accessible and measurable whole. It was quite a dilemma at times.
Overseeing all three methodological approaches, each vying for attention and priority
morphed the film into a multi-discipline focus. Who said documentary filmmaking was
easy? Engaging individuals who had serious subject matter to disclose and could be
affected by participating, being true to artistic process and line of inquiry using arts-
based research philosophy, and knowing that documentary film would be a measurable
academic piece for partial fulfilment of PhD requirements, was overwhelming at times.

This line of enquiry created many more questions than answers and with each
task and at different times the methodological approaches struggled for domination. I
wondered if all three criteria could be met in one creative process. As I alluded to
above, I wanted to be as objective as possible and yet I was a participant. My goal was
to ensure their stories were told. By observing, I was observational, yet, I was subjective
in how it all came together. I could not be completely objective because I was creating a
product that I was invested in.

As I write this section, I reflect back and smile at the pockets of imagination and
creativity that emerged in the process of film-making. It was a considerable task to learn
how to edit raw footage hands-on for over a year. I worked directly with a Deaf video
editor, who has been a colleague and close friend for more than 25 years. We had
worked together on other projects and had established a good working relationship. She
was very interested and concerned about the topic of death and was from the beginning,
instrumental in its making. Karen functioned in a variety of roles through the
documentary process. I am indebted to her for collaboration, insight and for joining me
on the roller coaster ride throughout the production and post-production of the
documentary. This was a deeply satisfying adventure complete with laughter, tears and
creative angst while editing 18 hours of videotape down to 35 minutes.

The process of editing, shaping, cutting and searching for final footage was
exciting and exhausting. It felt at times as though it were a never-ending saga,
consuming days and nights, a rerun of an old movie, with the button stuck on replay. The technical process sent my hair standing on end on more than a number of occasions. Often there were blocks to progress because we couldn’t figure out what we had done wrong. Humour, candour, commitment and patience and a firm belief in “it’s the journey, not the destination” saved our sanity on many of those long nights.

In the documentary and in the next chapter you will meet Hester, Joy Lynn, Russ, Maureen, and Larissa and Maxine. I will be discussing what was learned from the participants and the process. As a preamble, what you will see are completely different responses to similar events. Emotional variations are evident among the participants. Family dynamics often played a pivotal role in how individuals are affected. Deaf and hard-of-hearing participants reveal how access to communication affects all interactions with immediate family, extended family, the medical systems and funeral and service preparation and participation.

Individuals wanted to share their experiences to heal themselves but also for Deaf and hard-of-hearing individuals facing similar experiences. They did not want others to suffer and hoped they would have better communication options and understanding of what to expect when death stops at others’ doorstep. Whether you lose someone you love or are facing your own death, the process of being in Mortal time creates an altered state of being. There was the sense that time was precious and the desire to do it “right” whatever right meant to that individual, was paramount. All participants contributed a part of themselves because they wanted to contribute to the collective well-being of the Deaf and hard-of-hearing community experience. The end result is that the function of this documentary can be expected in some way to be educational in nature by enlightening all of the participants and the audience in some way. I did not attempt to follow any proscribed method of documentary conventions because that would thwart the whole purpose of making a “visual documentary” with Deaf and hard-of-hearing participants and confuse the creative process. The process was its own.
Chapter 4.

Narratives and Interpretations

Threshold

Why mourn for a cocoon
After the butterfly has flown?

Death is one of the few givens in life, and yet we fear it. We immaturity deny its presence or refuse to take it into account. In life, where so few things are stable enough to serve as true reference points, death is one of our few assurances.

Death is not an ending. It is a transformation. What dies is only our sense of identity, which was false to begin with. Death is the threshold of this life. Beyond it is something else, some mystery. We can only be sure that it is unlike this life.

Let us be unabashed in admitting that no one knows death definitely. The closest we may come is a supposed near-death experience, which, by definition, cannot be death itself. Alternately, we can examine other people who have died. We can look at a corpse. When we do, we see that whoever or whatever it was that animated that body is longer in force. Is that body our dead friend? No. Whatever it was that was the person we knew is gone. What use is there to mourn over a lifeless shell in a casket?

Death defines the limits of life. Within those limits, there is structure upon which to base one’s decisions. Whenever one deems that one’s life has been fulfilled, one can utilize death as the portal away from this existence.

(Deng Ming-Dao)

This chapter reviews participant narratives and summarizes what was learned through examining reoccurring themes in the narratives of the participants. This line of enquiry examined Deaf and hard-of-hearing individuals’ communication experiences when facing the death of a loved one or facing death themselves. The participants’ narratives were filmed at various times and locations. As a result, the visual
documentary became *Talkable* over time (see Appendix B). Narrations were reviewed repeatedly and the name for the visual documentary emerged through the process of paying attention. It was created in pieces over time. Listening, with my eyes to the participants (for several this was their first opportunity) to share the events surrounding the death of a loved one became something they were able to “talk about.”

Death is one of the few givens in life, and yet we fear it. We immaturely deny its presence or refuse to take it into account. In life, where so few things are stable enough to serve as true reference points; death is one of our few assurances. (Deng Ming-Dao, 1992)

The topic of death, examined in the previous chapters, is not easily discussed in society. This is more difficult for those who cannot easily create opportunities for the “unspeakable” to be discussed in their own language and audiological capabilities. It seemed a natural outcome of the editing process to name the film *Talkable*. For the remainder of the writing in this work references to the film and the participants’ visual documentary will be replaced with *Talkable*.

The self can only become what it truly is through the confrontation with death, by making meaning out of our finitude. If our being is finite then what it means to be human consists of grasping this finitude, in ‘becoming who one is’ in a phrase of Nietzsche’s that Heidegger liked to cite. (Critchley, 2008, p. 235)

Filming the narratives and interacting with the participants was a tender process. Each of the participants exhibited an emotional response and at times became momentarily overwhelmed. The narrative process was focused and specific to the question about how each of the participants coped with the loss of a loved one. Experiencing the participants' point of view meant temporarily leaving my own existence to enter theirs and experience their emotional and psychological reality. Seven participants agreed to be part of the enquiry. All but one participant, who was filmed, has been included in *Talkable*. One narrative from the raw footage that was acquired in Kelowna, British Columbia, and shot on the spur of the moment “didn’t make the cut.” This was due to technical issues in the shooting and transfer during post production. During the editing and cutting of raw footage, choosing and throwing frames onto the floor at times felt irreverent. And yet, in the end, the essence of the issues was captured
in the video. Also included in the film was a Hospice specialty nurse (Nan St. Eloi, R.N.), who’s professional perspective was invaluable.

Grace, a potential participant who was dying, had made contact early on to participate. We had met through the British Columbia Cancer Agency (BCCA). When I contacted her to set up film times, the participant declined to participate on two separate occasions. Chemotherapy had failed to arrest the spread of cancer. She reported that she was not well enough to participate. Another of the participants in Talkable was also receiving chemotherapy. As Maureen and I entered the day chemo room, Grace was sitting in the far corner chair. At first they couldn’t see each other. Suddenly, there was a flurry of hands, recognition of similar journeys and then they both engaged in an hour-long conversation in sign language about chemo, cancer and life.

I had been transporting, accompanying and supporting Maureen to chemotherapy on a monthly basis. I sat in the waiting rooms and chemo rooms, translating the conversations among the hearing patients with Maureen. On this occasion, though, I was struck with awe, during that chance meeting. Each had been receiving chemo for more than a year and somehow, on this day, chance played its hand and they had been assigned to receive chemo on the same day, in the same room at the same time. It was astonishing to witness their ease and comfort. The ability to converse in their native language about their illness, treatments and successes permitted them, if only temporarily, to stop thinking about being a stranger, as the only Deaf patient in a room among many hearing people. Both were busy exchanging information and sharing news and chatting about life. They were laughing from the belly, connecting from the heart. The needles, nausea, chemicals and the intimidation of impending death were momentarily suspended. Or was it? Perhaps they were just enjoying communicating with each other; they could communicate in their own language.

Two Deaf patients amongst a room full of hearing patients. Normally, they were the outsiders. In this instance their hands vibrantly dominated the air space. Hearing patients were mesmerized as they watched the animated conversations. These two women were living with cancer sharing similar experiences with cancer. Alive, not alone and could share some sustenance along the journey of life with someone else who shared a common language and culture. Watching the process of Maureen being the
outsider over the years, this day with Grace was very special indeed—they were now both insiders. Shortly after this chance encounter, Grace died in the spring of 2011. She was 50 years old.

**Reviewing Participant Narratives**

There was a certain kind of reverence and astonishment when I sat with the participants during filming and again later, when viewing people’s narratives. The ache and sorrow over their experiences associated with the death of a loved one was powerful. The editing stages allowed me the privilege of sitting with them for hours on end. Sign language is such a visual language and the honesty with which all the participants shared their experiences was extremely gratifying and moving.

*Talkable* was created so that the participants could tell their stories. Audiences would be able to directly see specific issues that affect Deaf and hard-of-hearing individuals as they confronted their loved one’s death. Each participant expressed a completely different response to the death of a loved one. Each participant used a different style of communication. All participants shared one commonality. Access to communication appears to have touched all layers of the family, the extended family and the Deaf and hard-of-hearing community. Family of origin dynamics of communication often played a particular role in each interview. Sharing their experiences of the death of a loved one, meant being submerged in historical emotions revealing suppressed feelings of exclusion and frustration, triggering painful memories. These included feelings of powerlessness, helplessness, non-participation and exclusion. Each of the participants expressed deep sorrow, frustration and anger as a result of having decisions or actions made without their inclusion.

In a regular workday, this in itself would be a frustrating occurrence. However, in those important moments of heightened emotional distress surrounding the death of a loved one, the obvious impact on the participants can be seen.

There was unanimous agreement amongst all the participants that interpreters and communicators would be a valuable assistance at diagnosis, treatment and any closing rituals of loving goodbyes, whether they be bedside whispers, family interactions,
funerals, memorials and graveside burials. Further, they suggested that the benefits of group therapy, bereavement therapy, loss and grief education could not be underestimated with these target groups. Coryell, in her book *Healing through the Shadow of Loss* states:

> individuals need time to reconstitute themselves after a loss. Not only has there been a death of someone in our life, but we too have died a death. It is not only the person, place or thing with whom we had the relationship that is no longer present, but the person we thought ourselves to be is also gone. (Coryell, 2004, p. 113)

Deaf and hard-of-hearing mourners share common experiences. They can't talk easily to other family members who are not Deaf. They have a lifetime of not being able to fully understand or be understood in normal everyday conversations and experience of work and family life. They struggled not only to participate in the rituals of closure with their dying loved one, they were excluded from participating or accessing opportunities for integrating experiences of loss with others in a structured healing manner. Having the opportunity to share those experiences with one another can strengthen the bond that comes with shared experience and assist them with healing and grief work. Certainly, isolation is a key factor with all the participants regarding communication when confronted with the death of a loved one. Not having the opportunity to integrate these experiences with others prevents them the opportunity of resolving them of painful issues of exclusion, lack of participation and of feelings that they didn't matter.

Reviewing segments in the following narratives may be a departure from the academic format normally found in this kind of document. This is a stylistic choice of language presentation embraced to capture voices attempting to retain the affect of the participants. I have wherever possible chosen to retain the essence of the communication from the participants who are Deaf by retaining elements of Deaf language. This means that English grammar and syntax will take a back seat wherever possible to emphasize the meaning as it was obtained visually and gesturally.

Because I think, like many of you, I think whatever we can discover, when it comes to a disruptive and constructive, it would have to be with openings for many voices, many voices that haven't been heard. And it's one of the things I take very seriously. I mean I know, as I think most of you know I have to be aware of where I come from, of my new situation,
not only about being a woman and being middle class and so on and so forth, have to be aware of the limits of my vision. Because I am that.  

**Meeting the Participants of *Talkable***

All of the participants are members of the 90% statistic documented in Chapter 2. They were Deaf children born to hearing parents. Each of the participants has different family constellations.

**Hester**

**Biographical Sketch**

Hester was born to hearing parents. She is culturally Deaf and uses ASL as her primary language. She is the mother of two adult Deaf daughters (both of which went on to become teachers of the Deaf). Hester attended residential school for the Deaf for all of her educational years. She married a Deaf man. She is a seasoned advocate and holds a variety of professional positions in the Deaf community. Her narrative discusses the loss of her mother.

**Her Story**

When she was diagnosed with cancer, Hester’s mother stayed in hospital and for two weeks Hester cared for her mother. Hester’s narrative highlights some of the frustrations she felt trying to care for her mother while not being able to understand her mother, the nurses and doctors. She articulates in her narrative that communication was a barrier to understanding her mother’s needs and she recounts that the experience was awful. Unfortunately for Hester, fond memories of caring, exchanging memorable deathbed conversations that could have been opportunities for closure between mother and daughter were lost. Instead, Hester’s remembrances of her last days with her mother are wrought with pain and helplessness. She eloquently expresses in the following segment that she wasn’t able to assert her communication needs within the health care setting.
In one of Hester’s early exchanges with her mother, her mother finger-spelled to her “I D I D N O T D E S E R V E Y O U.”

I was frightened to share my experience with just anyone. They could have created further harm by being negative about my mother’s comment. They could have misinterpreted it, too. I chose to talk to people I trusted, like my daughters or professional people who I knew would be positive. In order to protect myself, I had to pretend I was talking about my friend. I was afraid if they knew it was my mother’s comment, they would judge me and say something that would further traumatize me. I was too vulnerable to let them know that my mother had said that to me, because they could interpret it wrong and say negative things. (Hester)

Hester highlights the issues and barriers related to communication. If her mother had a need she was either too sick to communicate it or Hester was not able to understand it. In this instance both mother and daughter could not get their needs met. Mother was not able to get her health care needs met and wasn’t able to receive nurturing from Hester and similarly Hester was not able to give to her mother and fulfill her desires to nurture and advocate for her mother during illness. There seems to be two issues in the next segment: poor care for a hearing mother and inability to help her because she was a Deaf daughter without access to communication. When our parents or loved ones are sick, they need us to be their spokesperson. Hester says:

Deaf people need more support. It has taken me a very long time to sort out this particular experience and misunderstanding related to miscommunication with my Mother’s death. It has been very very hard. Counselling is needed. It doesn’t matter if they are Deaf or hearing, they need to have training on how to communicate with people who are experiencing issues relating to death. If they don’t have training they could say the wrong thing, they need to know how to listen and know how to provide comfort. (Hester)

Hester’s narrative relays the details of her mother’s decline. At first they wrote back and forth and finger-spelled to each other. As her mother deteriorated she was no longer able to communicate manually and the situation became unmanageable. As her condition worsened day by day, connection was replaced with an empty space between them.
What we stress with people and their families, although the person in the bed may not be responding is that they can hear you. When you think of someone who may be Deaf or hard-of-hearing, they don’t have that open for them. It’s quite difficult for someone who is Deaf or hard-of-hearing, if they are using sign language. They may not have the strength to continue to sign. So how do we help them? How do we help people when there are communication difficulties? (Hospice Nurse, Nan St. Eloi, 2011, participant in documentary)

Hester experienced feeling helpless and as she says was paranoid that something dreadful would happen and she wouldn’t be able to know what the problem was and couldn’t help her mother. Her mother finger-spelled to her “I D I D N O T D E S E R V E Y O U”. In Talkable, Hester recounts that moment as shocking, very shocking. Shocking, she says, because at the very moment that she wanted to understand her mother’s communication, she couldn’t understand the English meaning behind the finger-spelled words. She was helpless to understand the message from her mother.

According to Hester, they locked eyes for two minutes. She was unable to decipher “I D I D N O T D E S E R V E Y O U.” To ease the discomfort for herself and to appease her mother, Hester responded to her mother that she loved her. Again, her mother spelled “I D I D N O T D E S E R V E Y O U”. Hester was flabbergasted; she recalls not knowing how to respond to her mother, and the impact of this comment would haunt Hester. She was still unclear about what her mother was saying to her. Hester says:

There was no interpreter, “how could I express myself?” I couldn’t respond to what my mother was saying because I did not understand the meaning behind her saying “I D I D N O T D E S E R V E Y O U.” (Hester)

In this context, her mother’s last tender message was not only lost to Hester but it was also confusing, causing her considerable distress. Her mother was able to make eye contact with Hester; however, all Hester could do was smile her way through the moments, unable to understand the meaning behind the comment and incapable of responding to her mother.
Hester was traumatized and continued to obsess about her mother’s comment long after her mother died. “I couldn’t sleep.” Hester tossed and turned all night. “I just kept saying I love you, I love you. It was very very hard.”

Hester wondered if she had done something wrong. She surmised that perhaps she had not paid enough attention to her mother, or that she didn’t give enough love to her mother. Because she was not able to understand the English phrase, it left Hester with many unanswered questions. It shook the foundation of her mother/daughter love. Hester felt very unsure of herself.

‘Later, I asked someone to explain what was meant by. “I DID NOT DESERVE YOU.”

Hester’s daughters, who were fluent in ASL and English (bilingual and bicultural), were told about the event at the hospital. They explained to Hester the English meaning of “I DID NOT DESERVE YOU.” Although they tried to reassure her that her mother was saying she was a good daughter and that her mother felt that she was not good enough of a mother to Hester, Hester could not fully understand the comment nor accept the third-hand explanation. Even after the daughters had explained the English-ASL translation, that comment left her with a feeling that she was bad.

Hester discloses that she continued to have difficulties sleeping and was obsessed with the phrase. Night after night she was troubled by her mother’s last words to her. She asked friends whom she could trust, what her mother could have meant. She was looking for reassurance and understanding so she could integrate the passing of her mother.

The comment had somehow blocked her ability to believe that her mother’s last words to her had good intentions and were a declaration of sorts regarding her mother’s joy about her daughter. They were endearing words from a mother to a daughter. Yet, Hester couldn’t hear them, nor grasp the meaning. Over time, after many repetitions of: “I DID NOT DESERVE YOU” to friends and professionals, she started to accept that the words were loving and not critical, upsetting, unkind, hurtful, cruel, wounding and insensitive.
Hester suggests that the hospital experience could have been much different if an interpreter had been present. A quick interpretation of her mother’s expressed sentiment could have quickly been interpreted and Hester could have responded in kind.

The following summer, at a celebration of her mother’s life, there would be two interpreters. and finally Hester could feel relief because she could finally express the emotions and feelings associated with the loss of her relationship with her mother and honour her mother’s life.

Hester sees a need for services for Deaf and hard-of-hearing individuals who are caregivers providing support for hospital stays and visits for those who are facing life-threatening illness and death. She suggests that for Deaf and hard-of-hearing individuals, providing accessible communication is essential for their loved ones or for anyone who may be facing a life-threatening illness. Family members who either are Deaf / hard-of-hearing or have family members facing illness or death conceivably will have communication barriers. Providing access to someone who is both familiar with the processes associated with dying and death and also has cultural and linguistic capabilities to assist the caregiver with navigating the dying and death processes would be valuable.

Hester generously shared two more death experiences that had happened earlier in her life. The following two narratives highlight communication struggles within the family about death.

When Hester was 13 years old, she watched her favourite uncle fixing the roof. The next day she was informed that her uncle was dead. She did not understand what that meant. Hester and family attended the funeral. Hester recalls seeing the coffin open, walking up to the coffin and seeing the profile of her uncle’s face. In Hester’s words “POW SHOCKED SOBBED SOBBED HARD COMMUNICATION NOTHING.” Hester recalled that her mother was upset about her response. Hester was inconsolable. According to Hester, she was “very very shocked and traumatized and had nightmares.” These nightmares continued for three years after the funeral of her favourite uncle. Hester was clear that there was no communication in the home about the death or the funeral to help her come to terms with the death of her uncle. In her words,
“communication was blocked and that was her first experience of death.” She articulates that there was a lack of communication and each of them had severe traumatic impacts on her. As she says: “those memories were etched in my mind.”

Although Hester was traumatized by seeing her favourite uncle in the coffin, it’s not unexpected that any child at that tender age would be shocked and bewildered by the death and the ensuing rituals of funerals, including the confusion of seeing her uncle one day and then seeing him lying in a coffin the next day. The phrase, “here today— gone tomorrow”, has a significant place in this traumatic event. What’s not so clear in my mind is whether this has to do with barriers of linguistic communication or lack of communication about death and ritual embedded in the family dynamics.

My hunch is that it’s a little of both. The fact that her uncle had died and the family did not use sign language as a method of communication is important. Communication about death was probably not a topic that they were able to engage Hester in easily. Hester was dependent on environmental information given to her, so she would have missed some of the cues that hearing children would be privy to. Unfortunately, she was left to her own strategies to make sense of the experience and come to terms with the loss and shocking experience of seeing her uncle in the coffin. Hester continues with the story and shares that in later years she was able to talk with friends and over time she began to understand what she had experienced. Clearly, if the parents had been able to communicate, both about death and the loss of Uncle Cliff, in ASL, or if Hester could have heard some of the information around her, undoubtedly some of Hester’s shock and upset could have been mitigated.

When Hester was 16 years old, her cousin Barbara, whom she adored like a sister, was killed in a car accident. Her mother drove to Vancouver and informed Hester that Barbara had died and she remembers crying really hard. She recounts that her mother and father drove on to Squamish and that was the last she heard about it for quite some time. She did not hear about a funeral and for years she wondered about Barbara and where she was buried.

Long after she was married, she was still struggling to accept Barbara’s death. Hester tells a story that is common among all the participants. The issue of their
common story is about the lack of information sharing. Several of the participants shared stories about not being told information immediately or about information being held back about significant events. This habit only enhanced their feelings of isolation and exclusion. Hester says:

I found out my mother had not informed me that she had gone to the funeral. I was mad, angry, enraged, PISSED OFF, MAD, ANGRY. I talked to my mother about it. My mother then became upset. She did apologize; she said she thought I wouldn’t want to go because it would upset me. I felt very angry because I had not been informed about the funeral. We discussed it passionately and my mother felt guilty. I wanted to see where Barbara was buried, I was obsessed about her. My mother decided to take me and my husband to where Barbara was. We went there and I saw her grave site which allowed me to accept her death and put closure to her death. After seeing Barbara I was able to accept her death and also able to forgive my mother. (Hester)

Hester shares her stories in the hopes that changes for Deaf and hard-of-hearing families confronting death will come. The pain and suffering she shares on the emotional journey she travelled will have meaning and purpose. She lost her mother, her cousin, and her uncle. She understands that dying and death is loss and a natural grieving process, but for Deaf and hard-of-hearing people, unless supports are put in place, the suffering is compounded and the length of time for recovery is extended. She suffered from isolation and continued to lose sleep. She suggests that Deaf and hard-of-hearing people need to have a place to share their feelings, to share their experiences. She strongly recommends that Deaf and hard-of-hearing individuals need support and should not be expected to manage the death of their loved one and also to grieve in silence. She is clear that had she been able to share feelings at the time of her mother’s illness and death with someone who understood the death process, she may have been able avoid increased isolation and receive the necessary assistance to alleviate the many confusions and misunderstandings.

Lack of participation in rituals for closure surrounding the death of loved ones seems to preoccupy Deaf and hard-of-hearing mourners. Being excluded, and not providing information about funerals or permitting participation through interpreters, being given information days after the death, was a significant factor in the feelings of detachment and exclusion. Not being able to participate in funeral preparations, decision
making for funerals or memorials seems to extend the suffering and reinforces feelings of inferiority and helplessness. Acceptance, which is a normal approach for integrating grief, appears to be buried under feelings of anger and bitterness in the following participant narratives. In some cases, as we will see, they carry the pain and sorrow like any open wound that can't be healed until some form of closure is offered and experienced.

**Larissa**

**Biographical Sketch**

Larissa was born to hearing parents. She is culturally Deaf and uses ASL as her primary language. Larissa grew up in a hearing household with one hearing brother. She attended residential school for the Deaf for most of her educational years and has held a variety of entry level jobs throughout her life. She is 53 years old and a mother to two adult hearing children. Her narrative discusses the loss of her grandfather.

**Her Story**

Late to inform me..... Always the last to know..... Told me on Friday instead of Wednesday... Frustration in accessing interpreters, Many phone calls... All hearing, one Deaf. Me! No interpreter.... Meant I could not participate. I looked around and as the service continued I became angrier and angrier because I couldn't participate and I felt less inferior. I became inferior in my grief. Became smaller and smaller. No accommodations made for me. No interpreter. I asked my Mother to write the story down, I read script...... Could not follow what was going on in the service, tremendous frustration and exclusion. Being the only Deaf person at the funeral prevented me from speaking about my grandfather at the funeral. I wanted to communicate with him before he died. (Larissa)

Larissa’s' narrative, although short in length, reveals similar and important consequences about feeling excluded. This is especially poignant as she was the only Deaf person in a funeral service full of hearing people. Larissa angrily and passionately shares the frustration of being left out of another family life event and transition because she was Deaf. She could not follow the agenda or the service or the speakers who were asked to speak about her grandfather. She was unable to discuss the contents of the eulogy written by her mother with her loved ones. To draw attention to her frustration,
Larissa speaks very intensely about her position as an isolated mourner who couldn’t even understand the priest delivering the sermon.

Larissa, as you will see, is outraged. As she shared her narrative, she was reliving the experience and all the emotions associated with it. It becomes apparent that this event is only one of many events within her family of origin dynamic and her life in which she feels excluded. It is a theme, a family script, which has occurred throughout her life and caused her much suffering. As she recounts her story the reality of “exclusion” underlines her belief of unworthiness. The exclusion keeps her at a distance from the inside circle of her family. It is concretized through the rituals of death and the funeral service of her grandfather. This event recreates and reinforces a common theme that originated in her family of origin because of their inability to communicate effectively with each other. Communication barriers continue to exist today for Larissa, along with the painful realization for Larissa that her family will never learn to communicate in sign language. In her schema, they have once again reminded her of her “otherness.” She resents them for the exclusion and internalizes the event as a reflection of her worth. She recreates the helplessness she felt as a child living in a household that tolerated rather than embraced her deafness. She believes she is worthless to them. “If I were valued they would help me to get an interpreter they would inform me right away and they would consult me. They would consider my needs for inclusion and participation.” She tells us that she missed out on important family history. She believes she wasn’t told because she was Deaf.

You will see throughout her narrative a heightened level of frustration and an endless bucket of unresolved anger about being excluded. She could not follow any of the speakers in the service and therefore could not receive any words of comfort from them. Further, she could not partake in the ritual of collective public grieving and the socializing aspects that act as a buffer and healer in those moments of intense grief when people come together to do closure. Larissa, as you can witness in the film, was left to grieve on her own with little or no communication within the family or extended family.

This narrative is angry in its delivery; the exclusion aspect is repeated by the remaining narratives of the participants. One after another they expose the heartbreak of
not being able to hear the very things that made their loved ones special. Instead of focusing on the love and loss of the loved one and making sense of death and life, they instead are focused on helplessness, the loss of being included and valued, and the effects of exclusion.

**Joy-Lynn**

**Biographical Sketch**

Joy-Lynn was born to hearing parents. She is culturally Deaf and uses ASL as her primary language. She attended residential school for the Deaf. Joy-Lynn is 29 years old. Her husband is Deaf and they have two hearing children. She works as a one-to-one worker with developmentally-delayed adults in a day program. Her narrative discusses the loss of her mother.

**Her Story**

This participant reveals a certain mind-set of helplessness at the outcome of being Deaf and facing the health care system. Joy-Lynn can’t change the fact that she is Deaf and her family can’t change the fact that they are hearing. Nor can they modify years and years of patterns that have emerged from the family constellation. Now, her mother has cancer and they enter into an enmeshment with the health care system, which also functions on a multi-layer system. Deaf and hard-of-hearing individuals entering the health care system can be likened to foreigners within their own families, land and country. Family belief systems and behaviours associated with communication differences continue, although unintentionally, to contribute to misunderstandings, feelings of inferiority and rejection. This leads to a feeling of worthlessness. Communication is so important for connection, bonding, support and intimacy.

*My mother went for to the hospital for all day testing; I really wanted to go with her. Mother said “No, no, communication is too difficult.” She said I would be in the way because of communication. She said dealing with the nurses and a doctor was hard enough and having me there, was not a good idea for communication. My mother did not want the responsibility of communication for me and having to deal with the medical testing at the same time. I felt rejected by her because of barriers to communication.*

(Joy-Lynn)
As I reviewed this particular portion of the narrative, I found myself returning again and again to this fragment. As I watched Joy-Lynn, I saw an exaggerated flicker of eye rolling movement in Joy-Lynn’s facial communication that drew me in when she was talking about her mother. After repeated viewing, I could see it was definitely more than a blink. It appeared as though her blinking was a physiological response to her story and the feelings associated with rejection by her mother. Although it was a repetitive movement and it was automatic, I was reminded of the similarities that I had viewed in other narratives. Each of the participants, when disclosing painful feelings, used repetitive signs or words as a process to take the edge off the intensity of the emotion as they recounted the details. Did Joy-Lynn’s outward anger actually cover her buried hurt feelings as she recounted that mother/daughter exchange? I suggest that indeed, the eye rolling and blinking was her bodily response to the feelings of hurt and rejection that still caused her considerable discomfort.

In the following segments, we see that interpreters have been involved in the health care meetings which involved Joy-Lynn and family. The response from Joy-Lynn, although appreciative of having interpreters involved, is still exasperation. The behaviours of the interpreters influenced her experience in both instances. As I watched the film clips I began to realize there were no easy answers.

We had a family meeting with the health care team, brother…. The group of us were sitting around discussing the full situation with all the details. Most of it went right over my head, lots of discussion about medical things. Then suddenly the meeting was over, I had so many questions, I was overwhelmed …and in those moments of incredible emotions. I had forgotten to ask, and then suddenly no communication. The interpreter left and I was sitting there unable to communicate.

We got two interpreters for the meeting. While they were working they kept interrupting their interpretation to tell me how sorry they were for my loss. Sorry for your loss. Sorry for your loss. I did not want to be listening to them telling me how sorry they were. Why were they doing that? I wanted them to be focused on their work and not distracting me from the information in the meeting. (Joy-Lynn)

Joy-Lynn was very clear about how the interpreters’ participation in this case interfered with her process. As I reviewed the material, I wondered if cross cultural conflicts were arising from this experience. Extending condolences to someone who is
facing a life-threatening illness is a social norm in hearing culture. Perhaps, the interpreters’ timing was not appropriate in their decision to extend their condolences to Joy-Lynn during the meeting. Every linguistic and cultural group has its own way of seeing and expressing how it experiences and interprets the world and interacts with it. This includes interacting with loved ones, interpersonal relationships, families, medical professionals, hospices that are facing end of life issues. Often because of the communication barriers Deaf persons are excluded from full participation in the end of life stages of their loved ones. At the center of their core identity is ASL. Their position in society is likened to being a foreigner in their own country, without the removal of communication barriers.

Joy-Lynn did not accept the interpreters’ comments during the meeting as caring and instead viewed the comments as intrusive. In her mind, their comments were taking them away from the task of providing her with vital information. She was left with a negative experience. Bereaved persons may suffer not only sadness but anger and suspicions about the motives of people who offer support.

In the middle of meeting the interpreters get my attention to tell me they are sorry and they have to leave for other appointments—it was in the middle of my meeting—Imagine—meeting was not finished. I felt stuck. When it comes to anything related to death and dying, interpreters should stay until Doctors, nurses and social workers leave. Then it is appropriate for the interpreter to leave. Do not be the first person to leave. They should be the last to leave. It’s just not right. (Joy-Lynn)

On occasion, an interpreter has lost emotional control when they have been called to interpret for a doctor who is delivering news about terminal illness. It is in this context that the interpreters’ role is to act as a conduit and deliver information with impartiality or neutrality. Interpreters are human beings with lives and histories, which might include a recent death, unresolved issues about death or coping with cancer diagnosis themselves.

However, one can never be sure what individual triggers arise in such a delicate tense situation. Perhaps, there needs to be a certain level of intimacy before one can accept condolences and share vulnerabilities with interpreters. Maybe the interpreters were not considered intimate enough by Joy-Lynn to be commenting about her mother.
Their relationship was a business transaction of sorts and therefore she may have experienced their caring as crossing a boundary. The general rule in interpreting would be to take the lead from the other parties and follow with the same.

In the morning, I saw that my mother hadn’t taken medication or been fed. I freaked out and went to the nurse to tell her, she just stared at me. She knew that my mother would be dead in a few hours. I didn’t know that—why didn’t she tell me? "She should have, she should have let me know. I was disappointed. What’s the matter with her? She should have told me." It is very important to have someone explain what to expect and what you will see when someone is approaching death. The physical symptoms of dying are very known to the nurses. They could be difficulty breathing and body weakness and the signs are very important to follow and the nurse didn’t tell me these things. (Joy-Lynn)

I do not want to go through interpreters for issues related to death and dying. I prefer to discuss these issues with someone directly who can sign, and who has experience with death. Seeing someone who can sign, but does not have experience or understanding about death, they haven’t had the experience so how can I relate to that person. It’s important to have both someone who uses sign language and they know or have experience with death or dying. I can’t relate if they don’t. (Joy-Lynn)

What we tell family members and try to reassurance them that even though they are laying there and can’t talk to you, their ears are open. It doesn’t take extra work for them to hear you. It’s quite difficult for someone who is Deaf or hard-of-hearing, if they have been using sign language. They may not have the strength to continue to sign. So how do we help them? Most people are uneducated about how important communication is. Therefore, you have someone who has a disability and you realize just how much more important communication is to help that person whether they are the person who is dying or they are the person that’s grieving for someone who is in the process of dying. We rely so much on communication.

(Hospice nurse, Nan St. Eloi, 2011, participant in documentary)

Much of the interaction of Deaf people is impacted by the negative preconceptions and misunderstandings that so many adults have towards disabled people in general and Deaf people specifically. These interactions can understandably give rise, in Deaf people, to feelings of mistrust, anger and scepticism regarding the behaviour of hearing people, and may result in weakened ego development. Some evidence for this last assertion can be found in studies of Deaf children born to Deaf

These barriers are exacerbated for Deaf individuals who use ASL. As mentioned earlier, the Deaf community is primarily a visual community that uses a visual language (ASL) to express and receive information. In fact, for most individuals who use ASL, using English is a second language. Deaf people who use ASL are part of a larger community that has a core identity based on its linguistic and cultural traditions. That culture is commonly known as Deaf culture, sharing common values, norms, traditions, language and identity. Deaf culture, then, is rooted in a visual culture. This is evidenced through the many values expressed through their visual language (ASL), and most activities related to their culture.

**Maxine**

**Biographical Sketch**

Maxine was born to hearing parents and her first language was English. She received her first set of hearing aids when she was diagnosed with hearing loss at age seven. Maxine attended hearing public school throughout her educational years. Ten years ago, she had another significant decrease in her hearing and, since the research was completed, has obtained a cochlear implant. Maxine relies primarily on hearing-aids and lip reading to make her way in the world. Maxine is the mother of an adult hearing daughter and works as a professional employment counselor. Her narrative discusses the loss of her mother.

**Her Story**

She was post-lingually deafened in her early years. At the time of capturing this narrative she had experienced serious deterioration in her hearing over the last decade. She recounts the final month of her mother’s illness with cancer. She discusses openly the frustrations and the exclusion she felt at not knowing what was going on with family communication around her mother’s hospital bed. Finally because of her mother’s weakness and their communication differences she was not able to hear the faint whispers of either her mother or the information from the nurses.
The problem for me surrounded around medical professionals and family coming in sharing stories. I couldn’t hear and follow so I missed out on a lot of bonding and support for one another. I remember being at my Mom’s funeral or memorial, and I don’t have a word or clue what was said—to this day it is painful. It was such a significant part to celebrate her life. I really don’t know what anyone said. I sat in front row and yeah, I don’t know what was said. I remember the luncheon afterwards and trying to stay secluded, away from everyone. There were so many people, I couldn’t hear what was going on, too painful to put the work into trying to follow conversations and I just figured I wouldn’t be able to hear what was being said, it was easier to hide in a room. I’m pretty sure I hid in the kitchen with the sandwiches, trying to make and fuss over kitchen stuff, to try to avoid that communication end of it. Trying to deal with people asking questions when I didn’t think I could hear or follow them was difficult. I think that was probably the most painful part of my Mom passing away after was the communication part of it. (Maxine)

One can see how easily end of life practitioners, families, and medical professionals’ lack of awareness, can lead hard-of-hearing individuals to feel isolated and experience miscommunication and frustration. Communication barriers, then, are the catalyst for needless suffering for hard-of-hearing individuals interacting with end of life processes.

Incapable, incapable because I couldn’t, I couldn’t hear, so the nurses would come and say have you noticed any difference. I would shrug my shoulders and I would be like “I don’t know”. In a sense I felt that I was letting her down. I wasn’t being the caretaker I needed to be at that point because I couldn’t hear. (Maxine)

What we stress with people and their families, although the person in the bed may not be responding—they can hear you, when you think of someone who may be Deaf or hard-of-hearing, they don’t have that option open. I think that it’s essential to look at the whole person. What can we do to help them communicate to the person who is dying communicate. But also for the loved one communicate with that person till the end of life.

(Hospice nurse, Nan St. Eloi, 2011, participant in documentary)

If I was alone with her and she was in bed I was quite often scared she was choking and I wouldn’t hear. I was continuously putting my hand on her chest and throat to try to feel that she was ok. (Maxine)
People often say to me, “I don’t want to suffer” that’s when we do the pain and symptom management.
(Hospice nurse, Nan St. Eloi, 2011, participant in documentary)

I think that the most painful part of it was relying on my family to give me information and to give me ‘accurate’ information. That was the biggest thing for me, it was a trust, a trust issue for me.

Hearing loss is primarily a communication disorder; it affects both the individual who has it and those with whom she or he interacts. If the listener is hard-of-hearing or oral deaf and does not understand what is being said, the person speaking will also experience a communication problem. In the same way, speakers, as well as listeners who are hard-of-hearing, share responsibility for preventing or reducing communication problems related to hearing loss. Individuals who are hard-of-hearing cannot prevent or resolve communication problems by themselves; they often need the cooperation of those with whom they communicate.

I remember quite clearly sitting there. You know, not understanding, not knowing. I just smiled at everything, when everyone else smiled; probably hoping that nobody would ask me later about a story that was said. I really didn’t know what had been said.

As I learned going through the recent death of my friend, I was very much part of that process with the medical field and the family. At that point I had learned I was upfront of the fact I was deaf/oral. I was a lot more upfront about demanding them to write things down for me. I think I was wiser to what my needs were and I wasn’t quite so willing to be ashamed of my hearing loss. I really missed out on something significant that I probably shouldn’t have. You know, it’s a big loss for me. You can’t go back. Unfortunately, I mean especially when we are hard-of-hearing, many of us don’t sign. So it came down to asking people to repeat themselves, to write it out for me so I could see. Also the songs they played, they printed the lyrics ahead of time. I was able to really participate and be really aware of my surroundings and the feelings that came with it, helped me heal along with the rest of the group. (Maxine)

The frustration evident in Maxine’s narrative was both not being able to deal directly with medical professionals and Maxine’s family not relaying communication to her when they were all together at the mother’s bedside. Instead, when she asked what was being said, they would tell her it wasn’t important. The narratives demonstrate that indeed, it is very significant to relieve suffering or comfort a loved one during those final
days and hours. Based on this disclosure and others, it appears that attending becomes a central purpose of family members caring for their loved one. At this crucial point in her process and in her heart any communication was important. She relayed that it was vital to her involvement that any communication between any of the family members, including her mother, and nursing teams and doctors would have been helpful to her understanding and acceptance of what was happening.

For the patient who is dying comfort and reduction of suffering for both the physical and psychological suffering needs to be addressed with anyone who is dying. One of the very important things is that individuals have a sense of safety and comfort. They want to know they are going to be safe and that they are going to be well-looked after. They’re not going to suffer. Individuals who are dying want to deal with those left behind. Elderly spouse or family members, who’s going to look after loved ones or children left behind. How will family manage without me? Anything we can do to help resolve those issues or put in place funeral or arrangements and bereavement counselling. Most of us are connected to somebody; often we are leaving behind somebody of importance.

(Hospice nurse, Nan St. Eloi, 2011, participant in documentary)

Maureen

Biographical Sketch

Maureen was born to hearing parents. She is culturally Deaf and uses ASL as her primary language. She is the eldest of three daughters. The second daughter was Deaf (deceased in 1950) and third sister was hearing. Maureen said she was born hearing and, at age four, became Deaf. She and her Deaf sibling attended residential school, where they obtained all of their education. Maureen taught at Jericho Hill School for the Deaf for 33 years. She was the first Deaf teacher in British Columbia and is an elder and leader in the Deaf community across the country. Maureen is 94 years old and did not marry. Her narrative is different from the other participants because she is the only participant who is currently facing death. Her concerns about her death are reflected in her desire to have a place for seniors where she could have connection to her community and feel wanted.
Her Story

Maureen is living with cancer. She is the only participant in Talkable that is facing death. Chemotherapy is keeping her alive. She lives alone and she remains committed to life. She also remains committed to education, social responsibility and is very concerned about seniors who are Deaf and hard-of-hearing. In her narrative she shares that they are being isolated and uncared for by the fabric of our society. Facing cancer is a huge task by the average person, but to face cancer and not have access to solid support and connection to one’s community is a very frustrating lonely experience. Her narrative pleads for some attention and focus to anyone who can help provide Deaf, hard-of-hearing and deaf/blind seniors with a place they can feel wanted and a place they can call home. She believes a seniors’ residence would assist anyone Deaf of hard-of-hearing who is dying or facing a life-threatening illness to have an improved quality of life.

I called my family Doctor to find out what was wrong with me? My Doctor told me you have cancer.... I was completely broad sided... I was SHOCKED, and stunned.

Ambulance will take you to the emergency hospital. Doctor will be there. I wrote to the ambulance attendant, “Will there be Interpreters there?” “Yes, all the time they have different interpreters there.” I was so relieved. Interpreters will be there! That’s awesome.

I arrived at hospital, and I asked the nurse. Do you have interpreters here. She said “Oh yes. They have Japanese, Korean” and blah blah blah a list of many. I looked at her—“do you have Sign Language interpreters for the Deaf?” She looked at me with a stunned look and said “No.” I said “What?” in distress; “No sign language interpreter for the Deaf people?” She said “Yes, on call.” OH, frustration and despair.

Deaf and hard-of-hearing and deaf/blind need WHAT? a place FOR Deaf seniors. It doesn’t matter whether they are Deaf or hard-of-hearing or deaf/blind. WHY? If they find out they have cancer, they want to move to a seniors’ home to make people alive and social. Chatting with each other and engaged, talking they will forget about being sick. They will feel better because they have a place to communicate with each other and they will have support. SUPPORT. They can play games, and socialize, it’s very important. Communication is VERY IMPORTANT. Where do Deaf people get communication? In Sign Language. Yes, you can get support from your home, your children BUT YOU HAVE A STRONG DEAF CULTURE!!!!! You are bonded with your Deaf friends. Where will you will find that? You will find
it in a seniors’ place for Deaf seniors. So that is why we have been WAITING and WAITING for a place for seniors—a Deaf seniors home.

TRY TRY HELP!!!!!!! us old people. We are now aging and still waiting for the next generation and next, next, next, all those people will be moving closer to old age and needing a home too.... Older generations and those who are aging need a place....What will you all do and you may all stay there WHAT ABOUT US now.

WHEN will we have it? If someone gets sick or has an accident, or they may live alone somewhere they can move to seniors’ residence. Maybe they can get help and friends can visit and help. They can be in the same room with other people and watch games and they don’t have to be alone. They can participate in conversation as they want too. Instead many Deaf seniors are isolated from each other living alone in faraway places. They can all sit together and chat and not be alone. Make someone feel "W A N T E D."

I hope you will think about it and HELP any other people who may have cancer somewhere. We don’t know who has cancer now. If people are sick we must help them. Keep helping others who need it. Spread that help. KEEP in contact with all the people if you can. PLEASE never leave people who are sick, ALONE. If we had a place for Deaf seniors’ home... FINE FINE FINE cross our fingers. (Maureen)

Russ

Biographical Sketch

Russ was born to hearing parents. He is culturally Deaf and uses ASL as his primary language. He uses hearing aids to supplement auditory information from the environment. He was mainstreamed in hearing classrooms throughout his educational years. He is 59 years old and the father of three hearing children. He teaches ASL, and works as one-to-one worker with Deaf children and developmentally-delayed adults. He grew up in a hearing household with a hearing brother and hearing sister. He chose Deaf partners for his first two marriages, both ended in divorce. He currently has a hearing partner. His narrative discusses the loss of her mother.

His Story

I have many frustrations. This is a common experience. Something happened to father or mother and they wait several days to inform me. I am always the last to know. I want to know when it happens, N O W, not two or three days later.
So disgusted when this happens—postpone, postpone. They let me know when mother fell days later, they waited to tell me. I am always the last person to know.

My natural native language is ASL, speaking and lip-reading is not my first language. I am not in an equal position if I have to speak. I have to work hard to figure out what they are saying. I have to be careful of what I say. I have to think of the right word in English, instead of sign language. Using sign language allows me to speak from the inside out, expressing myself. Using lip reading and finger spelling, I can't express myself fully. It's very difficult. (Russ)

The following segment is another example of individuals who use sign language not being included in the discussion and decision-making processes of funeral and tasks associated with memorial services. This is a common theme, expressed by participants of the bereaved in this research. Using sign language is difficult to understand and, as such, many siblings and parents with Deaf children and later adults, never master the language well enough to have full discussions with Deaf family members. While they were growing up their communication was often truncated and superficial. This results in not always conveying important information. Because communication is more challenging, often families habitually handle their affairs and take care of business without including the Deaf person. This increases resentment and at times dependency, which diminishes their independence and self-sufficiency. It also, as we have witnessed throughout these narratives, creates complicated suffering and grief.

Where are Mom's ashes? My brother and sister told me they left them at the Crematorium. You left them there.... WHY? I wanted service with ashes. I was shocked. The ashes are not here. Why didn't you tell me? I exploded in rage. I was so stunned distressed. I couldn't speak. When I am upset I can't talk, I prefer to use American Sign Language. I had a laptop with me, so I called VRS—Video Relay Service. I phoned my brother. My Brother was in the same room. I phoned through my laptop to VRS, who called my brother. It was a 3-way conversation. My brother answered the phone, and refused to talk with me through an operator. He hung up. I made the call to VRS again. I told him, “I want to talk to you!” My brother again didn't want to go through VRS. He wanted private conversation. I kept phoning back; he hung up again and again. All told, I called him six times. Then my brother said he would accept the call from me. I used sign language to vent my frustrations and feelings about mother's service and about me not be included in the decision-making and, at the same time, I let them have it about growing up Deaf within the family unit and how I was excluded and
left out all my life from the family. My brother and sister were astounded at how I could explain myself in sign language through an interpreter. There was so much to say and they did not know I could say so much. They both listened while I said my piece, and it was a long piece.

After that call, I felt at peace. (Russ)

Listening to this portion of the narrative was a very poignant moment for me. Access to communication allowed Russ to call a video relay operator and have the operator express verbally everything he was saying in his native language in real time. There was no struggle to find the right English word, nor were his siblings struggling to understand sign language. The conversation went back and forth using a third party. It is not ironic, that in the world of Deaf communication, that Russ had to call a stranger, to have an intimate conversation with his brother and sister about very personal details of his mother’s funeral service. What’s also moving is that although Russ was enraged, he was able to take matters in his own hands and repeatedly called his brother until his brother accepted the call. He says:

Using interpreters robs us our privacy. Most interpreters work in community, socialize together; they know our business. I feel as though they are looking down on me.

Then I open up and start talking about feelings, and then they switch interpreters. I don’t want another one. Shit. My privacy and my interpreter are no longer there. (Russ)

This is a double-edged sword for Deaf people who use sign language. Access to communication needs to be gained through using sign language interpreters. Yet, by using sign language interpreters someone is always privy to personal information. Their personal affairs including doctors, financial dealings, everything in their lives is open for the interpreters to witness. Confidentiality is assured by professionals. However, having another person present at a major event involving your life also can create a sense of lack of privacy and leads to feelings of inferiority and judgement. I certainly would find it difficult to attend a doctor’s appointment and have a physical examination with an interpreter in the room, never mind, if I needed some kind of intervention for grief or spiritual crises and needed to disclose very personal information. I see Deaf people’s desire for access to communication as natural and human, and in my mind they are valiant individuals with determination and strength.
I want more ASL communication within the family and hospitals when confronting the death of a loved one. I have to depend on my brother and sister for information. It's very limiting. I want deep information, the full information. Not enough information. There is no way for me to integrate into the family at the time of Death without the proper accessibility to language. It puts me in a dependent position. I can't participate without communication as an equal. (Russ)

Some of the anguish we see in the narrative is related to closure rituals. Yet this also appears to have more to do with repeated experiences of exclusion within the family unit at such a tender time of death. All family members want to feel connected and know where they belong at the time of loss. Any perceived exclusion, real or not, triggers a torrent of unresolved rage for their real experiences of life-long struggle to not be invisible within the family unit. If not dealt with effectively, this could be considered the final exclusion. One so painful, it creates the crack that splits the cover and reveals decades of unmet needs regarding communication and drowns the voice of reason, compassion, compromise and flexibility.

Those who use sign language are at a disadvantage. Not being included in the discussions and decision making processes of dying and a bereavement service leaves many stricken with feelings of being disenfranchised. This is a common theme, expressed repeatedly by participants in this research. Using sign language is difficult to understand and as such many siblings and parents with Deaf children never mastered the language. Some of the anguish shared in this research is related to unsatisfactory closure rituals and also appear because of repeated experiences of exclusion, triggering a torrent of rage for a life-long struggle to not be invisible within the family unit.

The narratives reviewed in this chapter are based on personal communication experiences of Deaf and hard-of-hearing individuals regarding the death of a loved one. Communication barriers have dominated the lives of the individuals, and throughout this chapter they have provided us with direct feedback. These “voices” have enriched my understandings of what challenges appear when Deaf and hard-of-hearing individuals face the death of a loved one or when they face death themselves.

So I have to not only try to expand my own consciousness as much as I can, I have to listen harder than maybe I had listened in the past, and
realize how many voices there are, and realize how much credibility I have to give to voices that are different than mine. (Greene, 2004)

In the final chapter implications for education and future directions will be suggested as a way to respond to feedback and suggestion documented throughout this chapter.
Chapter 5.

Discussion

O dark dark dark. They all go into the dark,
The vacant interstellar spaces, the vacant n to the vacant,
The captains, merchants, bankers eminent men of letters,
The generous patrons of the arts, the statesmen and the rulers,
Distinguished civil servants, chairmen of many committees,
Industrial lords and petty contractors, all go into the dark.
And we all go with them. . .

(Eliot, n.d., III-1)

The final chapter will review the key findings, make recommendations and suggestions based on the research in the scholarly writing and the video documentary Talkable. As death took up many rooms in my house I had many unanswered questions. I questioned the meaning of life and death. Deaf and hard-of-hearing people shared personal experiences about death and funerals. I questioned what they experienced when confronting the death of a loved one. Had their experiences with death been okay? What themes appeared over and over? I began to question value and beliefs. How do I feel about my death and theirs? How do others feel about death? I noticed death, heard and saw death. In the concluding chapter, the research will answer how this research has contributed to our understanding of how Deaf and hard-of-hearing individuals cope with the death of a loved one. And then, specifically, what can we bring to Deaf and hard-of-hearing people who are dealing with their own death or someone else’s? The main objective of the line of enquiry was to examine communication issues affecting Deaf and hard-of-hearing individuals facing the death of a loved one or facing death themselves through arts-based research. At the out-set, we can safely say that, indeed, arts-based research was successful in this research. The making of the documentary film exposed a variety of communication issues surrounding death and Deaf and hard-of-hearing mourners.
The narratives of Deaf and hard-of-hearing mourners confronting a death situation are significant sources of information. The documentary film process involved a group of individuals exploring communication through the lens of death, using creativity as its vehicle. The result is a documentary that exposes their stories, concerns and experiences with the healthcare system, their families and funeral service industries. Those in a power position can make fundamental changes to policies involving end of life care for Deaf and hard-of-hearing individuals.

They have provided us with valuable data obtained through direct arts-based research. We have learned through the narratives that anyone facing a medical process, or who is dying or facing death most often has someone waiting or hovering in hospitals rooms or halls nearby. The participants also outlined in the previous chapter substantial details of critical end-of-life barriers to communication and concrete information that can be transformed into tools for change. Undoubtedly, any change to accessing the health care services, bereavement services, and improving family communication would improve the experiences for Deaf and hard-of-hearing individuals.

This research inquiry is grounded in theory; this arts-based research is sometimes characterized as ambiguous because of the emotive qualities evident in the questions asked at the outset, which are then expressed as sensorial, emotional, and/or intellectual processes of coming to know throughout the inquiry. (Sinner et al., 2006, p. 1238)

Facing the Death of a Loved One (Participants)

An agreement was made to all the participants that the Talkable documentary would be available for viewing before submission. Further, it was agreed that if any part of the film was unsatisfactory, changes could be made and if in the end, one wanted to withdraw from the creative process, their narratives would be removed. It was also decided that any feedback they provided would be included in the final chapter. Upon completion of the film, a meeting was set up at one of the participant’s homes. All the participants were invited to the viewing without being told who would be involved. Unknowingly each one had participated without the knowledge of the other. This was to be their first meeting. I hired a sign language interpreter to assist with communication for ease of the process. Both the editor of the film and I facilitated the group viewing.
Several themes emerged from the documentary viewing. The first theme conveyed was that the narratives captured were transformed into a realistic representation of their experiences. Equally important, was the accuracy of the message they wanted others to see. They were saddened that they had all experienced similar experiences and had suffered in isolation. The experience of participating in this research had made the participants consciously aware of the lack of services they endured. Coming together to view the film was both a relief and a horrible reminder of the pain they experienced because of communication barriers while dealing with the death of their loved one. Participants were happy with their messages portrayed in the film and expressed appreciation for the creative process of dealing with issues of communication through the making of a film.

All participants expressed the desire for the Deaf and hard-of-hearing community to have a course or a series of workshops to discuss and review the many steps involved with someone who is dying. They wanted specific factual information about physical changes during end of life stages and how to care for someone who is dying. They wanted to know what to say and what not to say. Requests were made on learning how to deal with wills, worldly possessions, family communication, body disposal, funerals and memorial services. They requested that resource people assist the community, perhaps by holding a town hall meeting to show Talkable and to discuss death and dying. The participants agreed that Talkable be used in any educational capacity including hospitals, palliative and hospice services and bereavement or counselling services to expose the hidden barriers and make a positive impact on the lives of Deaf and hard-of-hearing people.

They requested that bereavement counselling be made available during the dying process and after the death of a loved one to assist them with coming to terms with the loss. The end of life care and death of their family member created unresolved feelings of grief in isolation for a long time. They argued rather persuasively, that this needed to be addressed immediately.

They urged me to convince those who could help that Deaf and hard-of-hearing individuals, should be trained in palliative, hospice services and this included working with immediate and extended families. They articulated that the linguistic and cultural
aspects of Deaf and hard-of-hearing communities and the factual and educational material about end of life care and death be combined to create specific programming. They expressed fear that another death situation could happen and there would be no support, no bereavement counselling and no information on what to do. They did not want to re-experience feelings of isolation, exclusion and extended grief again.

Although interpreters would be helpful, the participants did not feel that interpreters alone would be able to satisfy their needs when facing their own death or the death of a loved one. Another participant, talked about the need to reduce the need and dependency on ASL interpreters.

They argued, rather convincingly, that any services or programs dealing with palliative services, hospice services or hospital death, needed to incorporate a Deaf or hard-of-hearing component, so that individuals are not isolated and left alone to deal with the effects of losing a loved one. They specifically requested a training program to be set up of selected Deaf and hard-of-hearing people to be trained as resource people to provide end of life support in whatever communication method is needed. The participants stressed the need repeatedly for grief counselling to deal with any unresolved feelings of grief.

Discussion expanded into the different emotions revealed by the individuals in Talkable. Although they were all different, there was consensus that the context of their grief was a shared experience and very painful. Communication was not only frustrating; it left them with feelings of hopelessness and helplessness, not only as a care giver but as a participant in the rituals of socially acceptable methods of closure. One participant appreciated the use of doors slamming on conversations, demonstrating visually blocked communication. This metaphor for their experience of being excluded had wide appeal.

The different emotional responses by the participants viewing Talkable, to seeing similar communication barriers and the narratives of one another was very moving. In particular, one participant expressed her delight that there was such variety of emotional responses. Shedding light on the impact of communication barriers which prevented them from participating fully in all aspects in the death of their loved one was important.
She said the range of responses were necessary and painted an accurate picture of real responses to circumstances that needed to be discussed. One participant stated that as a result of participating in this documentary, she was able to do some healing and felt really positive after having told her story. One participant asked that we add an additional comment to the end of the film. As the participant discussed this, the remaining participants were very moved by her desire to share that she had finally been able to talk to her mother posthumously through the use of interpreters.

She told us that she attended her mother’s celebration of life 6 months after this film was shot and was able in a private ceremony with family to “speak to her mother” through an interpreter. On the table before her sat an urn with her mother’s ashes and she was able to tell her mother the following: “Mom, You did deserve me.” She said that she felt that she had been able to resolve the turmoil around the parting words of her dying mother, which she hadn’t understood, which caused her many sleepless nights and left her very isolated. Hiring sign language interpreters to attend the private family memorial enabled her to finish unfinished business. This request was honoured.

One participant shared that she was aware of some support grief groups: however she was not able to find one that matched her specific age group. As a younger participant, she wanted to join a bereavement group of her age, believing they would have more in common than those of a more elderly group.

Deaf and hard-of-hearing participants gave us valuable feedback on current communication barriers that affected them deeply during the dying and death of their loved one. The emotive substance and content of the interviews allowed me the opportunity to think more deeply about their death experiences, communication and accessibility.

They wanted to discuss how horrible, difficult, unfair and powerless it was to be excluded in those crucial days, months and moments. Each and every person discussed at length the details of communication barriers that had caused them considerable pain. They hoped that things could be better for individuals facing similar death situations in the future as they interfaced with their healthcare systems, the funeral
systems, and family systems. In other words, they did not want their participation in this research to be futile.

When I think about my own experiences with death, I can recall being initially troubled by the complexity of the medical system. After the death of each person in my life, certain images of medical scenarios replayed in my mind. The memories had their own timing and there was no logical reason for their arrival and departure. Having the opportunity to discuss details, expectations and engage in minute by minute interaction with nurses, doctors and caregivers granted me comfort during difficult long nights of sitting with death. It also gave me the illusion of control. I suggest that the power of knowledge and information is unquestionable in coming to terms with reality and in many ways helps us cope.

It wasn’t until after their deaths that I was able tell and retell those incidents until I had found some relief. I learned that the act of dying is hard and difficult work. Caregivers witnessing the death of a loved one are in a heightened state of anxiety, stress and experiencing anticipatory grief. I was afforded the luxury of communication throughout the process of their end of life care and deaths. I could communicate with the experts and with all of my family members during the end of life stages. Afterwards, I was able to deal directly with the experience and grieve. I could ask questions. As painful as these experiences were, this process allowed me to be on the inside of the experience.

In the case of the participants, they were physically present with each of their loved ones; however, they could not participate, communicate or obtain crucial information. They were not able to get factual up to date information during the process or receive guidance about what to expect. This also means they could not get any comfort or care in dealing with the unexplainable or the mystery of death as they tended to their loved one. In the case of healing from the traumatic experience, the participants were excluded from opportunities to discuss grieving processes. Due to their specific trauma and isolation they were not able to tell their stories. If they remained traumatised long after the death of their loved one, this could be attributed to the lack of communication and sense of being outsider to the death experience and the healing process. I would have to conclude that they were not able to do proper closure or at the
very least, closure was held at bay because the experience was more traumatic. Participants did not receive compassionate support for their loss. They could not participate in funerals, memorials or celebrations honouring their loved ones. They were unable to share memories, or partake in stories with families and friends. The bonding in grief is normally reserved for public rituals to say goodbye. They were excluded from this very personal and public community and family occasion. For those participants who embrace a spiritual belief, a clergy's words of faith and comfort were lost to them. In some cases the participants were not able to hear the eulogy. This is appalling to my sensibilities. Death is one of the most significant experiences that we face and to have the added distress of exclusion and silence resulting from communication barriers is tragic.

The gift of this line of enquiry is that the participants were able to talk about their experiences and express the trauma associated with the communication barriers. GENERously, they have given us their stories and prudent suggestions for improving communication surrounding death customs. Communication needs are essential to deal with the necessary losses that illness and death brings. We make meaning by coming to terms with loss. We reshape who we are as we learn to live without our loved ones. And in some small way this encourages us to come to terms with the reality of our death. Each death brings us closer to ourselves and assists us to prepare for our final journey.

This original arts-based research is the visual evidence of their experiences with death and communication. Changes, even minor changes, can improve the quality of the death experience for all those involved with Deaf and hard-of-hearing mourners. Participants chose to discuss their painful experiences in a public format because they wanted to be reflective about their experience in their native language and video-taping narratives was the most direct avenue. Narratives obtained by capturing videotaped interviews in sign language formed the basis of the documentary questions and as you will see provide the beginning to solutions to unresolved grief. A secondary purpose was they trusted that by sharing their story, some good would come out of it.

The original video-taped interview data were the foundation for the making the documentary Talkable. Others before me have used the resources of multi-media to
capture experiences through arts-based research to answer questions related to education.

Penberg’s dissertation creatively used the resources of multi-media to produce what he called an “abecedarian” of educational experiences. His dissertation is an innovative documentary that capitalized on his long artistic and professional commitment to video production.  

(Sinner et al., 2006, p. 1230)

*Talkable* and the body of this dissertation functioned on two levels, as a documentary that incorporated still and video images, footage shot in many locations, narrative interviews, voiceover, sound, music and captioning, and as an arts-based representation of the personal experiences of Deaf and hard-of-hearing individuals facing the death of a loved one or facing their own death.

Educators have the responsibility to provide the space and platform for educational reform in the context of learning. Future directions will be recommended in the hopes that future guidelines for services providers, families and communities assisting Deaf and hard-of-hearing mourners with confronting the death of a loved one or facing death themselves can be less traumatic and more meaningful to all the stakeholders.

The significance of the research inquiry to the field of education may be explicitly stated or not stated at all. If the significance is not stated, the researcher may intend that the audience create meaning from their own situated perspective. Openness is a cornerstone of strong arts-based research. In this way, arts-based research encourages more dynamic knowledge construction in the academy as the significance is not always bound by the researcher.  

(Sinner et al., 2006, p. 1238)

**Facing Her Own Death (Maureen)**

Death is the final destination of what we call life and we are all on that road. In the middle of this academic and creative work, Maureen became extremely sick and was diagnosed with terminal cancer. Maureen is receiving chemotherapy treatment and has faced the realization that her life will end because of cancer. The shock of the diagnosis stunned her. She was 92 years old at the time. This led me to observe that no matter
how old you are the finality of life comes as a shock when it’s your turn. She became a participant in the research and our relationship, as we navigated her illness together, became a subject for this dissertation. I viewed it as a privilege to share her journey. The intellectual exercise of examining death had morphed into direct experience with a Deaf senior finding her way through the maze of medical treatment with a terminal illness. A loud awakening reverberated that our relationship had just cross over into “mortal time”.

In our work, we use “mortal time” to mean the experience of human beings confronting the prospects of death.

(McQuellon & Cowan, 2010, p. 6)

Once the interview process was complete with Maureen, I made the commitment to travel the journey with Maureen so she could access communication and healthcare. There was one significant difference with Maureen’s narrative. She did not really discuss the diagnosis of cancer in the interview very deeply. Instead she focused extensively on communication issues she faced accessing the hospital system. Her narrative was deeply reflective and focused about the needs of dying seniors. She was unwavering in her concern and her repeated requests for services for seniors are who are facing illness and death. She was particularly concerned about emotional and end of life care, physical deterioration and housing issues, and the psychological and well being care of seniors. Although, Maureen’s narrative did not share a common theme with the other participants, in the sense that she did not discuss the loss of a loved one, the researcher decided that the lone voice of the one participant facing her own death would be included.

My commitment to travel this journey with Maureen and ensure she accessed the medical system without communication barriers was a direct result of the research and a life-long career of working with the Deaf and hard-of-hearing community. There are no specific seniors’ services available or accessible programs for Deaf and hard-of-hearing seniors. They remain isolated and unable to access a whole host of services, programs that are available to hearing seniors. The diagnosis of a terminal illness and the natural declining health factors that come with aging added a variety of complications to an already anxious situation for Maureen.
When mortal time is entered with the diagnosis of a serious illness, it may stretch from days to years, with patients encountering both helpful treatments that lead to periods of remission and reoccurrences requiring additional treatments. (McQuellon & Cowan, 2006, p. 14)

Appropriate health care and quality of life issues became a balancing act against time and illness. Taking on the role of coordinator, companion and at times interpreter in “mortal time” gave me an insider’s view of the challenges and obstacles that confront Deaf and hard-of-hearing people facing death.

The interval between living and dying that we are concerned with here is not chronological time, measured in days, weeks, and months. The hallmark of mortal time is the person’s unique biological, psychological, social, and spiritual experience of the prospect and meaning of death, a prospect that confronts their caregivers as well. (McQuellon & Cowan, 2006, p. 15)

I was disturbed to see the enormous communication obstacles Maureen faced as she tried to access services, programs and resources connected to her treatment. The medical professionals we encountered, although kind and compassionate, were at times working at cross purposes. It was apparent to me that the cultural norms for the Deaf and hearing worlds clashed, furthering the complications of communication. Maureen needed to provide accurate information regarding symptoms and used a narrative style of communication. Doctors were interested in facts and yes and no answers, which provided little room for storytelling. Deaf culture values direct and to the point communication which often includes graphic descriptions and details. Many of the medical professionals we encountered were reluctant to use such a direct communication style.

Deaf and hard of hearing individuals desire for reassurance is a universal emotional need for security and orientation. Obtaining facts and evidence is a relatively neutral experience, however, how these facts and evidence are personally interpreted is a subjective feeling, affecting an individual’s sense of security. It is not helpful to offer a Deaf or hard of hearing patient false reassurance.

False reassurance places the Deaf or hard of hearing patient in a stressful state as he or she attempts to interpret ambiguous messages concerning the severity and implications of the disease. It is not helpful to offer false reassurance; it is palliative for the care giver, not the patient. Staff should explain sudden changes in a patient’s care and ordinary
routine (e.g. absence of regular doctor, new tests, change of diet, any delays, etc.) to the Deaf patient as soon as changes are anticipated (not after they occur). Staff should not leave the room without reassuring the patient and should never have a conversation in front of a Deaf patient and then walk out without explaining the gist of the conversation. If a conversation concerns a patient, include the patient or move the conversation elsewhere!

Be calm and reassuring with the Deaf person who verbalizes in the guttural manner of the deaf who have never heard sound or who have learned to speak by imitating the sounds felt with the hands on the throat and mouth of a person with normal speech. It takes time and patience for the hearing ear to become accustomed to this form of speech. The Deaf, dying patient can sense attitudes of non-acceptance and frustration on the part of listeners. If the patient perceives impatience he or she may become reluctant to express needs and feelings. But if he or she senses that special sense of care about him or her as a person, the patient usually endeavors to make care givers understand deeper thoughts and needs. (Salladay & Agustin, 1984, pp. 260-261)

Maureen needed continuous access to medical interpreters, doctor’s appointments, blood transfusions, eye doctors, dentists, pharmacies, occupational health services, working closely with community health care nursing, sign language interpreters, palliative care, lawyers, medical assessments and treatment meetings homecare services, foot care, and communication with the extended family during visits.

The most compelling aspect of my researcher role with Maureen was having the opportunity, both informally and formally, to communicate about life and death. Based on thousands of hours of conversations and extensive interviewing with all the participants, Deaf and hard-of-hearing people who are dealing with death and dying experiences emphasized communication barriers. Being present to their processes required a great deal of listening in a distinct method (watching very carefully) and letting go of my own thoughts, ideas and assumptions. Having the cultural and linguistic familiarity and capability to be in constant communication without the use of a third party (sign language interpreter) was a blessing and a curse.

It is a great responsibility to accompany anyone in mortal time. They expose their narrative and we see their vulnerability. They reflect on the meaning of their life or the life of their loved ones. The sacredness of this task each and every time we met was not lost on me. Personal narrative in essence is the story of our lives. The story of their lives
as expressed is open to interpretation. This interpretation is developed through the partnership of storyteller and listener.

When someone enters mortal time directly, their caregivers enter the same “time zone” vicariously. How they speak and what they do in mortal time together affect the quality and meaning of life for all involved, in the moment and beyond.

(McQuellon & Cowan, 2006 p.15)

Her “life review” began in earnest soon after diagnosis. Each visit, appointment, or meal provided another opportunity for listening with my “eyes and heart”. This became an important part of her end of life process. We were able to communicate directly in her language. We often ventured into topics that were normally reserved for immediate family. However, her family did not communicate in ASL, requiring me to communicate with family members about her well-being, wishes and needs. Some family members experienced pain and jealousy as they recognized that communication barriers prohibited the sharing of deeper reflections and intimacy with Maureen.

I would say that being a student of death vicariously, in a variety of capacities throughout this research, has sharpened my lens, increased my awareness and brought life into focus. The process has changed me from the inside out. As the end approached regarding this body of academic work, Maureen also approaches the final stages of dying.

At least now I know how I will die, I have always wondered how I will die. You don’t know how you will die. We all know we are going to die, but we don’t know how. Now I know how I will die and it brings me some relief.

(Maureen)

Maria Joyce, Senior Lecturer at University of Lincoln (2008) suggests that narrative may be used in shaping the presentation of an individual’s view of how they see themselves inspirationally and literally. Culturally it can be used to facilitate the sharing of belief systems and the positioning of shared values (Barthes, 1975). Narrative has been defined as first and second order (Carr, 1997). The first order narrative is where the individual tells the stories of themselves or about themselves, classified as ontological narrative. The second order narrative is the researchers’ account of the other stories used to present explanations of social and cultural
knowledge, described as representational narrative (Somers & Gibson 1994). Narrative is broken down into elements of social context where from one perspective the focus is on the individual, the interaction and narration of their everyday lives and conversations, the “…joint actions in local contexts and the other, where the focus lays with the individual within their social environment and society in general…. Into wider negotiated social worlds” (Plummer, 1995, p. 24).

During each interaction, I had to be very careful not to overlay my own narrative into the conversational space and often found myself entering into a “holding tank of silence.” I was waiting for the right response to emerge from within even if the content of the narrative that I was listening to or (watching) was painful or uncomfortable. Each narrative required a response and in the meantime eye contact was never lost. Every word and choice of sign vocabulary that I formulated in response was measured carefully. There were long periods of silence for us both as we held the narratives in mid-air. There were also wonderfully rich, long and frank discussions.

Final Thoughts and Suggestions for Change

The narratives of the individuals you have met within this original research provide stories of authentication and also new voices for information related to the study of death. These are the voices, witnessed by us, through their hands and eyes that need to be heard. Each portrait reveals a personal narrative. Each family has their own dynamics. Each death experience is individual and unique. To have the option of being included in all aspects of life and death decisions is to feel included, whether it’s good or bad. Deaf and hard-of-hearing individuals want to be included.

These voices help us build a better understanding of what learning and teaching environments are needed to support and enhance greater access to services that most of us take for granted. These voices challenged my assumptions of accepted methods and procedures of communication systems that are developed and in place to assist those in life threatening situations and personal crisis. There was a specific request that nursing programs, medical programs and educational programs that serve the needs of the dying and their families, have access to this documentary. The outcome of making
this documentary publicly available would provide the space so that changes could be made, policies could be developed, services and programs could be implemented.

There is an abundance of death-related literature, movies and resources available to hearing people navigating the subject of death, dying and bereavement. Deaf and hard-of-hearing individuals are a unique linguistic and cultural minority community with diverse needs. They are cut off from the hearing world by virtue of their audiological status and as a result are subjected to systemic marginalization and face multiple culture, language and literacy obstacles.

Deaf and hard-of-hearing individuals on average have lower reading and writing skills than their hearing peers. The abundance of available information and resources either through written or media formats are virtually impossible to access for the signing Deaf individual. Serious decision making often occurs when those closest to us are dying or we are facing a terminal diagnosis. The multitude of tasks associated with death and disposal of the body, burial and service rituals are overwhelming for the average hearing person. The problem of exclusion and relegating Deaf and hard-of-hearing people to outsider status must be changed if we want to be a society that cares about the dying and death experience for loved ones. It is time that we look for proactive solutions to communication barriers that prevent them from being able to participate fully in life and death decisions.

Referring back to Salliday and San Agustin (1984), Zieziula (1998) and Allen, Meyers, Sullivan and Sullivan (2002) in the Chapter 2 literature review, these findings also confirm (directly from the narratives) that not being familiar with deafness adversely affects access to healthcare for individuals facing death. The narratives revealed that Deaf and hard-of-hearing people who were dealing with the death of a loved one were unnecessarily traumatized by the lack of access. The participants exposed feelings of helplessness and exclusion when dealing with their loved ones who were facing death in hospital settings. Particularly, important and revealing was the findings that communication barriers extended into rites of grieving, funerals and memorial services. Again and again participants revealed experiences of not being able to participate in rituals of grieving or decision making regarding their loved ones.
The current research found that indeed, not only would access to sign language communication ease the process for all those connected to dying and death both within the family and in health care settings, but also found, sign language communication is essential during funeral and memorial planning and services.

The research extends the existing research in several ways. I wanted to know what happened to the individual when they face their death or they faced the death of a loved one. By involving participants directly in an intimate, powerful process, the research heard “saw” directly from Deaf and hard-of-hearing mourners. This research is important because the participants speak for themselves. They provide powerful testimonies of their experiences, both highlighting the trauma associated with the death of their loved one and subsequent trauma with access to communication within the family unit. By capturing the narratives in native ASL the current research contributes to existing information.

As mentioned in Chapter 2, 90% of deaf children are born to hearing parents. The participant narratives in Talkable clearly expressed family of origin frustration with communication while growing up. The intensity of the family communication history was exacerbated at the time of their loved one dying or passing. They re-experienced barriers to being understood and being able to understand. These narratives reveal the ongoing disappointment family of origin dynamics and participants reveal the powerful reoccurring theme of issues connected to language socialization.

The research built on previous research and extended our thinking about and understanding of mourners who are Deaf and hard-of-hearing. First, family of origin dynamics significantly dominated the narratives of all the participants. It was a powerful reoccurring theme. There lies a powerful fact. All the participants were children born to hearing parents who did not use sign language effectively. By encouraging the participants to speak for themselves, recurrent themes of language socialization issues emerged in the participant’s narrations. The research specifically revealed how the language socialization of childhood, affected them and their loved ones as they approach the death of a loved one. The research revealed that the direct experience of Deaf and hard-of-hearing participants language barriers were re-enacted in the dying
and final stages of the death of their loved one and they were traumatized. As a result of this research serious gaps in service were articulated by the participants.

Further opportunities are needed for healthcare professionals, educators, researchers and Deaf and hard-of-hearing community members to work together to create opportunities for dialogue that can create policies and procedures and or enhance existing services to include services and programs that serve the Deaf and hard-of-hearing community to prevent further trauma.

Salladay and Agustin (1984) do provide several significant suggestions for best practices to respect the process of end-of-life care when dealing with a Deaf or hard-of-hearing patient. Personal dignity is an important aspect for caregivers to consider. The patient may undergo examinations by medical personnel that require disrobing. They are often required to partake in medical procedures where privacy is minimal, and as a result their own sense of identity is lost. While physical privacy losses related to illness are unavoidable, emotional and psychological stress is not. Attention to thoughtfulness and tact, as well as the basic knowledge of communication strategies for Deaf and hard-of-hearing individuals, can enhance a patient’s sense of dignity. Dealing with a Deaf or hard-of-hearing individual facing end of life stages need extra time, so that medical professionals and caregivers can inadvertently avoid communicating rejection while being rushed or mechanical in their context. The mechanics of communication so that information is clearly understood, takes more time.

Health care systems, family systems and educational systems can assist individuals who are Deaf and hard-of-hearing to cope with the death of a loved one. Communication at the end of life is important for Deaf and hard-of-hearing patients, doctors and families (or the Deaf and hard-of-hearing family members of a hearing patient).

Death is a silent yet eloquent teacher of truth. Death is a teacher that speaks openly and yet is [not] easily heard. Death is very much present in our modern world: and yet it has become an enigma to that world. Instead of understanding death, it would seem that our world simply multiples it. Death becomes a huge, inscrutable quantity. The mystery of death, more terrible and sometimes more cruel than ever, remains incomprehensible to men who, though they know they must die, retain a grim and total
attachment to individual life as if they could be physically indestructible.  
(Vardley, 1996, p. 551) 

Individuals interfacing with end of life caregivers, the death service industry, and the heath care systems are families in crisis. We can become more aware and proactive in creating a climate of accessibility and communication. Educators can foster appropriate innovative opportunities for inclusion of Deaf and hearing perspectives in curricula. We have heard from the people directly and we can do something to make the journey of death less burdensome for all those involved. Cultural, sociological and psychological perspectives of death could be incorporated into courses for teacher education programs. The more familiar we are about death the more we can assist individuals to live more fully.

Recognizing the need for adequate communication, service providers in hospitals, cancer agencies, palliative care services and hospices, can create programs for Deaf and hard-of-hearing individuals. Perhaps these services could be itinerant services in the initial stages.

These programs could provide a training program for interpreters and support workers to address the needs of dying patients. Programs could have trained volunteers that work with existing palliative services that can also serve the Deaf and hard-of-hearing patients and their friends and families. Volunteers are important to any program especially if no interpreter is available when a Deaf patient needs to communicate. Providing an interpreter in the last minutes or in the moments before death is important however, early intervention with friends, families and nursing care is important.

A person spends years coming into his own, developing his talent, his unique gifts, perfecting his discrimination about the world, broadening and sharpening his appetite, learning to bear the disappointments of life, becoming mature, seasoned—finally a unique creature in nature, standing with some dignity and nobility and transcending the animal condition; no longer driven, no longer a complete reflex, not stamped out

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11 Thomas Merton’s “Preface” to the Vietnamese edition of *No Man Is an Island.*
of any mould. And then the real tragedy….that it takes sixty years of incredible suffering and effort to make such an individual, and then he is good only for dying. (Becker, 1973, p. 268-269)

In the West, we seem to forget that death is a part of life. Becker’s quote solidifies my belief that transformation from fear of death through acceptance is a necessary step in the journey we call life, and we need help and support along our way. Deaf and hard-of-hearing individuals deserve the same support on their journey.
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Appendix A.

Guidelines for Interviews

Communication Experiences of Deaf and Hard-of-Hearing People Facing the Death of a Loved One

Application Study Number: [2011s0205]

Research instrument semi-structured.
Interviewer is fluent in American Sign Language

Preparation of Interview
- Location and time
- Establish Communication
- Build General Rapport
- Focus the interview
- Explain research
- Confidentiality
- Arrange for resources as needed: grief support resource person

Attention to the After Needs
- Offer support: thank, believe, empathize

Completion of Interview
- Review the situation
- Explain the course of action step by step ("I will be doing... ")

Capturing the Disclosure
Examples of open-ended questions:

*What:*
- Can you tell me what happened?
- Can you tell me more about that?
- What happened first, then what? next? next?

*Who:*
- Who was involved?

*When:*
- When did this happen?

*Where:*
- Where did this happen?
- Was there anyone around?
Where were the other people?
Where did you go after the situation?
What did you do following the situation?

How:
How did you cope with the situation?

Impact on the Participant
How has this affected you?
Did this change your life?
Do you have any suggestions for Deaf and hard-of-hearing individuals who have lost a loved one?

Reasons for Documenting the Interviews on Video Tape

Pros
- standardizes the interviews
- non-interrupted interview
- full access for review by the interviewer
- captures the emotional, cognitive, behavioral and physical responses to the interview
- less possibility for communication errors
- standardized process and reviews for accuracy
- more culturally appropriate ie, no paper and pen, eye contact, direct communication
- attends to the overall needs of the person during the interview

Cons
- more expensive to facilitate
- need to spend time reducing fears regarding confidentiality concerns
- participants could be triggered by emotional content
Appendix B.

*Talkable* (DVD Documentary Film)

L. M. Franchi (writer, director, producer)

Deaf and hard-of-hearing participants in this research provided candid and moving portraits of their experiences with health care workers, extended family, and funeral and memorial events in video-taped American Sign Language narratives. These narratives formed the foundation for this fully accessible American Sign Language, sound, music, voice, and captioned documentary film entitled, *Talkable.*