

Creative Community Based Research

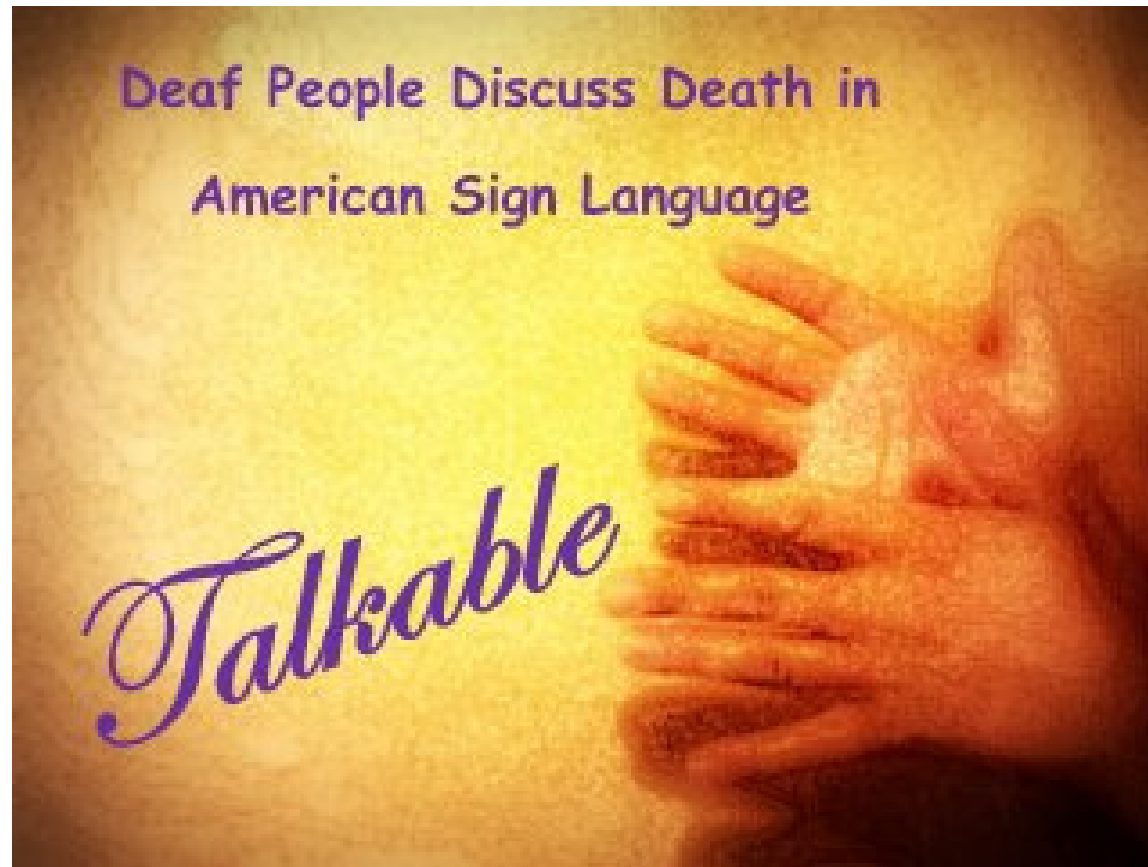
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Talkable

- What can Deaf people teach us about the death of a loved one?



Emotional Variations



- Understanding and navigating Deaf culture is a necessary framework for researchers to understand variations in emotions with Deaf individuals who experience the death of a loved one.

Line of Enquiry

We asked individuals to share their experiences. We used open ended format which yielded over 20 hours of videotape.

- * What happened?
- * How did they cope?
- * What did they do after?
- * What was needed to improve the situation for Deaf people?

Specifically we asked for strategies for family, health care professionals, church, social workers, memorial services and funerals?

Research Methodology



- It was decided to interview individuals directly in American Sign Language on videotape about their experiences of facing the death of a loved one or facing death themselves.
- To use those narratives as a foundation to make a documentary film with the participants having the final cut and the power to determine how it was going to be distributed.

The Big Challenge



The majority of the world controls the institutions which, in turn, controls education, socialization and enculturation of the majority of Deaf people.

Sensitive Topic



How could we as researchers tackle such a difficult topic as death. Our society has sanitized death and yet we are bombarded with images and experiences of death.

Dealing with a topic of death often evokes pain, memories, unresolved issues, anger, sadness, helplessness, abandonment and heartbreak.

Implications

- This research is important because the participants speak for themselves.
- They highlighted the trauma associated with the death of their loved ones and subsequent trauma with lack of access to communication within the family unit, healthcare and memorial rituals.
- Narratives reveal the ongoing disappointments within family of origin, and of similar childhood exclusion dynamics and reoccurring themes connected to language socialization as a child.

What We Learned



Communication is critical for any death and dying process and services such as bereavement and loss recovery programs in American Sign Language are vital for Deaf and Hard and Hearing people to integrate the loss of a loved one experience of death and dying.

Specific findings



Deaf narratives surrounding the experience of death revealed:

- Each family had their own family dynamics
- Each death experience is individual and unique and includes caregivers and loved ones.
- Inclusion in all aspects of life and death decisions, is to be included, whether its good or bad.

Specific Issues Emerged



- Lack of access to vital information about their loved one.
- Appropriate communication among family, healthcare and memorial-funeral rituals and bereavement services.
- Repeated exclusion from aspects of the process of dying and death of their loved one, created feelings of frustration, isolation, and worthlessness.
- Particularly important was the finding that communication barriers extended from the family member to healthcare settings and the rites and rituals of grieving, bereavement trauma, funeral and memorial services.

What We Learned



Death

Obstacles

Isolation

Issues for Mourners



- Accessing services, programs and resources connected to death, dying, bereavement, and loss, was a serious obstacle and often Deaf people had nowhere to go.
- Deaf and Hard of Hearing individuals desire for reassurance, is a universal emotional need for security and orientation after the death of a loved one.

Line of Inquiry



I experienced multiple deaths in a short period of time. Although my experiences were very personal. I believed my experience was no different than anyone else's. Death is a universal experience and although the details of death remain unique the experience is universal.

Line of Inquiry

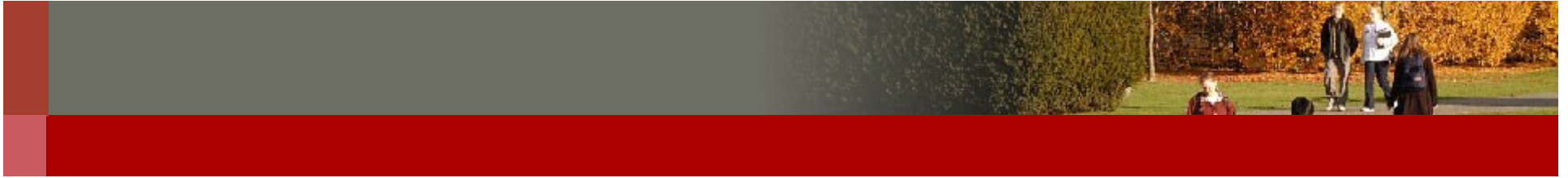
Then I had an experience. I was chatting with a Deaf community person who had lost her mother. I offered the following in sign language

- “Sorry about your mother.”
- She looked away and down.
- What did she sign to me???

Deaf Expression



“Gone accept.”



- Her response made me very curious about the emotions associated with death and Deaf people. Ironically I began to see this expression of sign language more often as I spoke about death.
- We wanted to find out what Deaf people went through when faced with a death of a loved one or facing death themselves.

Understanding their Needs



- However, emotions are always influenced by culture. This raised a bigger question.
- How are emotions experienced, expressed, perceived, and regulated by Deaf individuals facing death of a loved one or facing death themselves.

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