

Thanatosensitivity: Death in the Age of Electronic Communication and Its Relation to Information Overload

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Abstract Through a combination of surveys, personal interviews, prior experience, and analysis of research previously done on the topic, the concept of death within the electronic communication and socializing realm is discussed. The results of the surveys are displayed and recommendations for actions companies moving in this realm should employ are created. The primary goal is to answer the question of whether it is worse for a company to provide too little information on the deceased or if by leaving too much information about a user on the web they are plaguing those left behind with too many reminders of those who have passed. This is becoming a more important concept to consider as time passes, companies age, and the number of users who commonly use electronic communication methods and who are also close to the limits of mortality increases.

Author Keywords

Death; information overload; electronic ghosts; digital remnants; mourning; Thanatosensitivity

Introduction If you go to the current Facebook page of Jacob the comments and actions performed on the page resemble many of those found on most account profiles. Birthday wishes appear, though there are fewer than expected in the era of the Facebook birthday message explosions, pictures that appear to be from recent events, and messages of endearment from friends. Its not directly clear that Jacob differs from most users of Facebook, in that he died in a car crash in 2008. Looking closer into his profile and this becomes more apparent, with users noting that Facebook no longer is alerting them that his birthday occurred recently, a connection to a group in his memory in the search results, and a general lack of ability to properly search for his name.

Jacob's profile displays some of the steps that Facebook has taken to deal with the end of one of their users. The question posed in this paper is whether these actions, and other actions being performed by various forms of electronic communication, are enough. Are they helping those left behind? Or are they hampering the mourning process and prolonging the memories that may be beneficial to some but harmful to others. The term 'Thanosensitivity' appears to have been coined within a paper written by graduate students from the University of Toronto for the 2009 Computer Human Interaction competition. This word is meant to sum up the concept that mortality, dying, and death all heavily impact the full plans of any modern communications website.

Within this paper four primary sources were used. A survey was created via Qualtrics.com and distributed to a combination of sources. Three in-person interviews were performed, to gain deeper insight into examples how death impacted people's social media interaction.

Research papers discussing similar perspectives on the subject were also looked into. Beyond these, the author of the paper is drawing on prior experience, having lost someone who fits into the three main realms used in the survey: a family member, a good friend, and a more disconnected acquaintance.

Limitations of this paper include a limited pool being used for the survey methods and the reduction in time to find beneficial users to interview. The general focus in the initial survey was also perceived to only relate to social media websites, when the audience was intended to answer in relation to any form of electronic communication (ie.: emails, texting, voicemails, etc.) so the responses given may not have properly reflected the full experience of those performing the survey in connection to death and their electronic communications. There was also a limitation in the full comfort level of the author in discussing the subject with those solicited for interviews. While the response for interviews was positive, some volunteers had deaths connected via social media that were a bit too harsh and raw for the author to feel comfortable discussing openly.

Approach As previously mentioned, four primary methods were used to obtain information for discussion in this paper.

A survey was sent out using Qualtrics.com. The questions used in the survey are viewable in Appendix A. They used a combination of questions aimed at gathering statistics on those being surveyed, finding out just how many of them had experienced a death connected to their social media presences, and then attempting to figure out how they felt about the current methods being used by websites and how they felt about the various 'electronic ghosts' left behind. The results of the survey are displayed graphically within the Findings sections, and a full display of the answers given is displayed in Appendix B. The survey members were obtained by emailing various mailing lists the author was connected to that had members who were likely to be both social and fairly highly connected electronically. These included:

- *University of Michigan Architecture Students*
- *University of Michigan School of Information*
- *All Hands Active, Ann Arbor Hackerspace*
- *i3 Detroit, Royal Oak Hackerspace*
- *Linux Users Group of Michigan Tech*
- *PFRC of Michigan Tech*
- *Michigan Tech Student via Facebook*

The majority of replies came from the School of Information, with 38 responders. Respondents identifying as 'Other, was second at 12, and i3 Detroit was third in responders at 10. 42 respondents

identified as female, 33 identified as male, and one identified as trans. The youngest respondent was 19 and the oldest was 68. The majority of respondents were between the ages of 21 and 37. Overall, 79 users responded to the survey, and 56 fully completed the survey.

Three direct interviews were also performed. The volunteers were obtained by emailing the same lists used for the surveys and soliciting volunteers. Of the six volunteers, three were spoken to. The other three were turned down due to time issues and depth of connection to the loved ones lost (the author was not comfortable discussing children or direct family members who had died.)

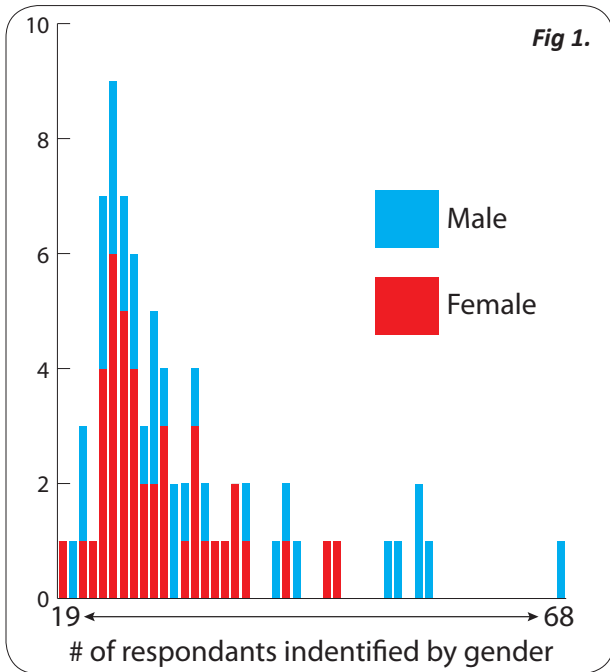
Four research papers were also included for consideration. *"HCI at the End of Life: Understanding Death, Dying and the Digital"*, *"Connecting Generations: Preserving Memories with Thanatosensitive Technologies"*, *"Death and the Social Network"*, and *"Dying, Death, and Mortality: Towards Thanatosensitivity in HCI"*. These are all prior papers written in connection to information science discussing death and its connection to digital mediums. These

his senior year of college, of a close friend who was deeply connected to others via Facebook. Additionally an aunt was lost last year, who had minimal social media presence, and a student from a prior job died during the summer after graduation. All three display examples of how social media can have positive and negative affects on the mourning process. These primarily worked as inspiration for creating the various survey and interview questions and providing initial hypothesis on how social media is affected by death. More in depth explanations appear in the findings.

Findings The results from the various sources were interesting, with some supporting the initial hypothesis of the paper and others tearing it down.

Survey To begin with, it was notable that not nearly as many of the users surveyed had lost someone yet in their life, who had a connection to the user via some sort of social networking site. If the surveys were to be redone, a question would have to be included to inquire whether the user questioned had lost anybody in their lives, regardless of connection via digital forms. More than half of the respondents surveyed had lost somebody, whereas far fewer had lost a direct family member, at least one whom they were connected to via social media. Most people had lost someone who they considered a close friend.

The number who had lost a more distant acquaintance was also fairly small, though this may have been due to a misunderstanding in the survey. These results are also influenced by the average age of respondents being fairly low. Conversely, when asked how web connected they considered themselves, almost all the participants rated themselves highly, between a 7 and 10. This can be combined with average number of friends



were paired with articles from The New York Times on the subject and inspection of the current protocols being used by selected social media websites. These primarily aided in shaping the initial hypotheses of the paper along with determining what questions to ask within the survey.

Last of all, prior experience from the author was looked upon. The example given in the introduction is based upon a death encountered by the author in

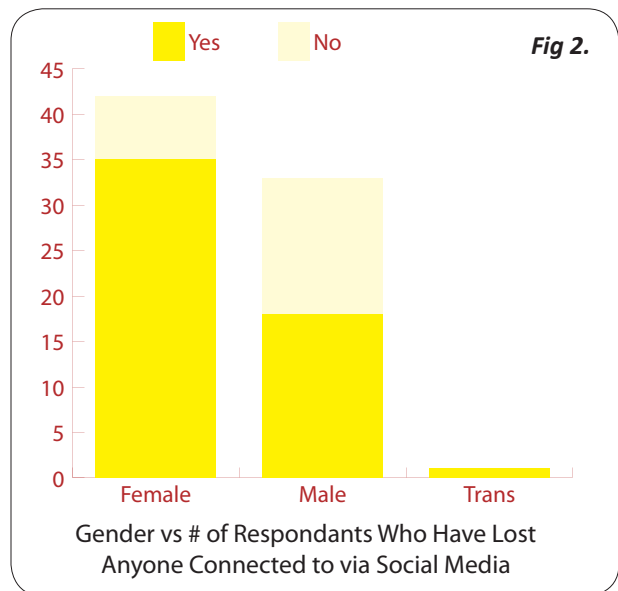
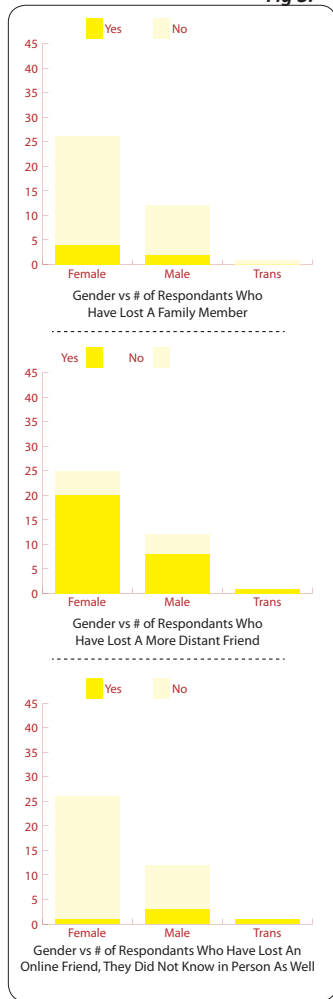


Fig 3.



the respondents had, with over 50% having over 250 connections and a third having over 500. This implies that the participants had a large pool of connections from which deaths could have occurred. Figures 1-3 display the backgrounds of the correspondents.

Finding #1 - Currently, not as many users of social media websites have experienced the impact of death upon their electronic communication as expected. This is likely to change though as the active population ages with time.

A major part of the survey was inquiring on people's personal experiences, which connected to the survey, and asking them to tell their stories. A surprisingly large of respondents provided fairly lengthy responses. These gave insights into how the respondents perceived the questions and give deeper info into their connections. For example, when asked if they had lost a family member connected via social networks, users gave the following examples:

- Mother, with occasional sent via Facebook
- Brother of a high school friend
- A good friend, newly connected on Facebook
- Sister-in-Law, talked via email
- Grandfather, via family website
- Cousin, Facebook friends
- Father, friend on Facebook
- Grandmother, via email and phone
- Three friends, photos posting and texting

From this group it was asked if they had any remaining social presence. Examples included:

- The memorial site was taken down and there are no more remnants on the internet.
- There is a shrine dedicated to the friend, with people talking to him as if he was still alive.
- The Facebook profile is still public so other peoples posting show up, and Facebook keeps recommending him as a friend.
- Still on Facebook but because she wasn't a friend she can't be added now and I can't see her wall.
- Grandma posts on Grandpa's profile giving the impression he's posting.
- Articles, obits, and photos still show up.
- The Facebook profile is still active, and it was difficult to memorialize it.
- Email messages that I just can't bring myself to delete.
- I just removed three from my account, two had been inactive, one was continued by his wife.

A similar question was asked in regards to the users more indirect friends with responses such as these:

- A friend from High School who died in Afghanistan.
- Classmate, colleague, talked rarely via social networks, more often face to face.
- Old school friend, posted and messaged on FB.
- Great grandfather, heard via family he had passed.
- A boy I went to high school with, wished him Happy Birthday and looked at his pictures.

These display that the view of whom a friend is much more varied than the direct family connection. The mention of a great grandfather is notable. The examples of their online remnants also differ notably from the direct family members:

- Her best friend had her log-in info and had a terrible time dealing with her death; for example, she posted messages under her name describing heaven and how it felt to be dead, telling us all not to worry about her. It was quite morbid. I "de-friended" her when I was finally done grieving about her death. It felt like a real life step.
- For a while, both friends Facebook pages were still active and people were leaving comments about their lives and condolences to their families. Both pages have since been taken down and not been replaced with any memorial groups or anything else to my knowledge.
- It's odd that his Facebook account and Twitter handle

still exist. I couldn't bear to look at either after his passing, but many in my circles still "mention" or "@" him in their status updates. I refuse to do so for personal reasons that I believe his spirit should be allowed to rest in peace. Also, I just find it creepy that a deceased person can still have an account months following. Seems there should be sensitivity and concern for the family/friends.

- They had a Facebook site, and it was recently taken down. My fiance is also friends with this person, and just last night mentioned that he saw this IM go online. I think his mom may have his computer now, so she probably didn't realize that was happening.
- I had to block him on Gchat because it was too painful (I think his wife signs on to check emails still). He is regularly part of Facebook's "suggestions", which is similarly upsetting, but I feel weird "unfriending". His name appears online constantly due to his profession (music journalist).

The responses in relation to friends were notable in how they seemed to have an overall more negative feeling. While the memorials had some positive implications, overall there were more negative feelings. There also seemed to be more examples of ghosts being left behind, in the form of electronic sign-ins that continue to connect and work after the person is gone.

Last of all, users were asked about their more distant connections, people they did not see in person often or potentially ever:

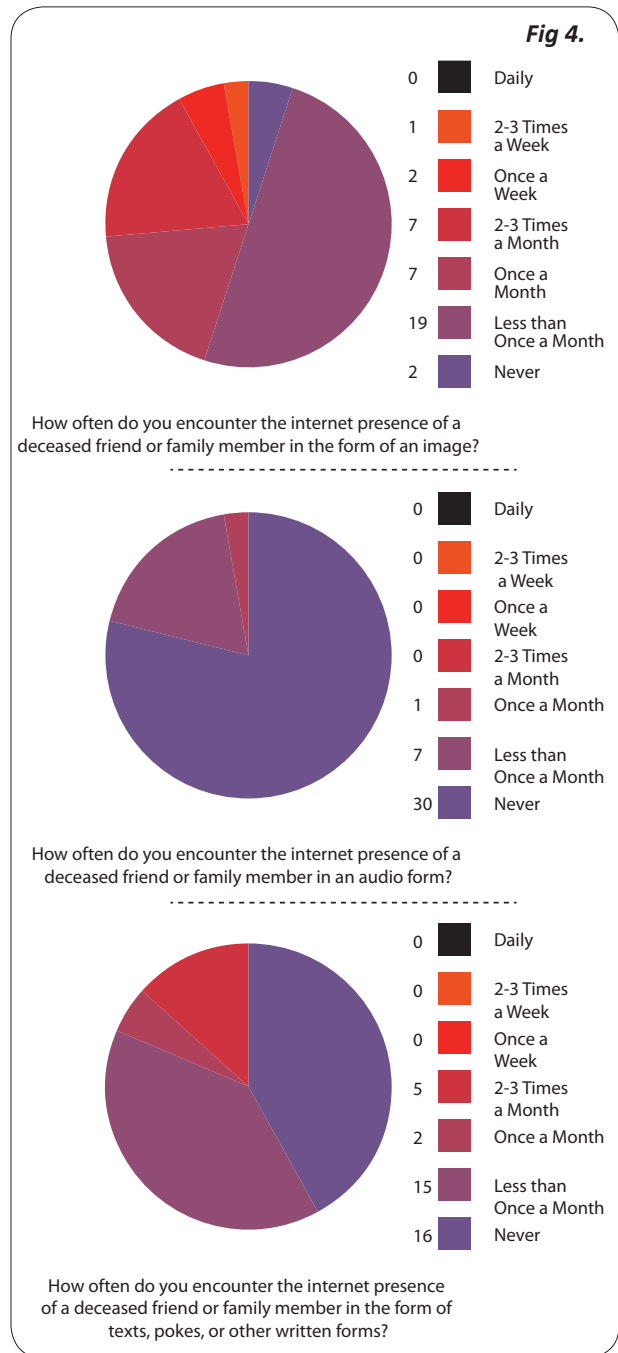
- Fellow fanfic writer, wrote some fanfic together.
- Another blogger who died of an overdose.
- Online friend, exchanged messages online.

This group did not receive the number of respondents I had hoped for. The blogger replies were the intended audience, with the goal of thinking about internet 'celebrities' people were connected, writers or bloggers who the user knew but had rarely met. The responses of connection here were similar to the family connections, being a little less connected or morbid:

- Memorial posts/fanfics.
- The person still has a few social media sites online, with blog posts and pictures still intact.
- His Xanga is still there. I haven't looked at it in years.

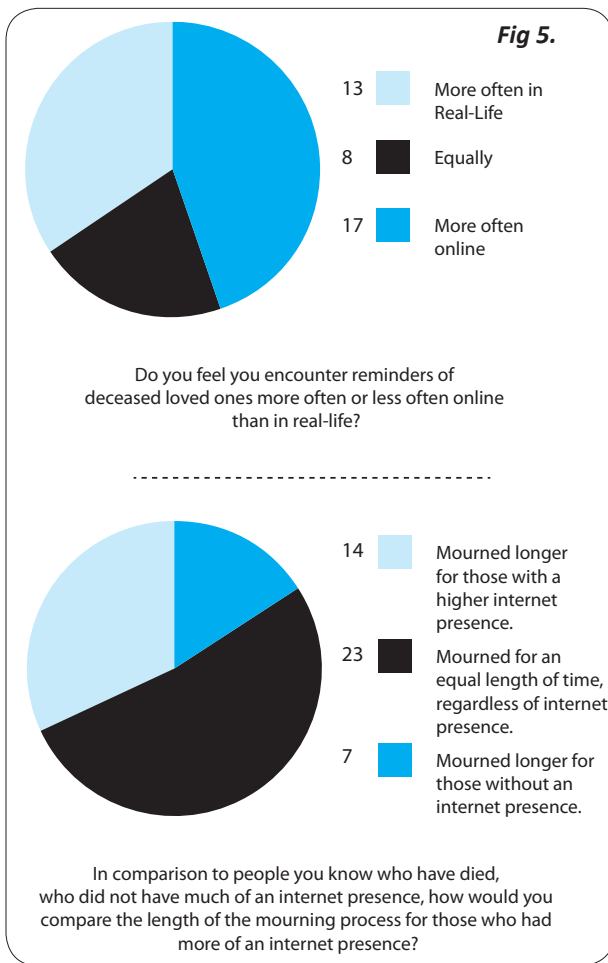
The specific notes provided by users provided greater insight into the exact feelings of the users in regards to their different connections via social media.

Finding #2 - While memorials to family members and distant friends seem to have a neutral or positive impact, the remnants from friends appear to be less controlled, resulting in more negative or morbid remaining connections left online.



Users were also asked about the persistence and number of times they encountered lost connections. The primary results were that their encounters with electronic remnants were fairly rare and primarily in the form of pictures and images. Messages were also fairly common but not nearly to such a large degree.

Finding #3 - Regardless of positive or negative, online encounters with electronic remnants were primarily on a monthly basis and mostly took the form of images or written work.



The results for inquiring on whether respondents found they encountered reminders of the deceased more often online or in real-life was mixed. There was a slightly higher number who felt they encountered reminders online. The wording of the question may be at fault, but it also may simply be that we are still early in the times of having multiple electronic deaths in our lives. Most people felt that an internet presence had no bearing on the length of their mourning process, but for those who felt reminders had some sort of impact, twice as many felt an internet presence caused them to mourn longer.

Finding #4 - Electronic presences have a slightly higher impact on reminding people of their deceased loved ones, and appear to mildly prolong the mourning process.

Respondents were also asked to generally comment on general positive experiences they'd had as a result of the connection between death and their social media connections. Some of the more notable comments included:

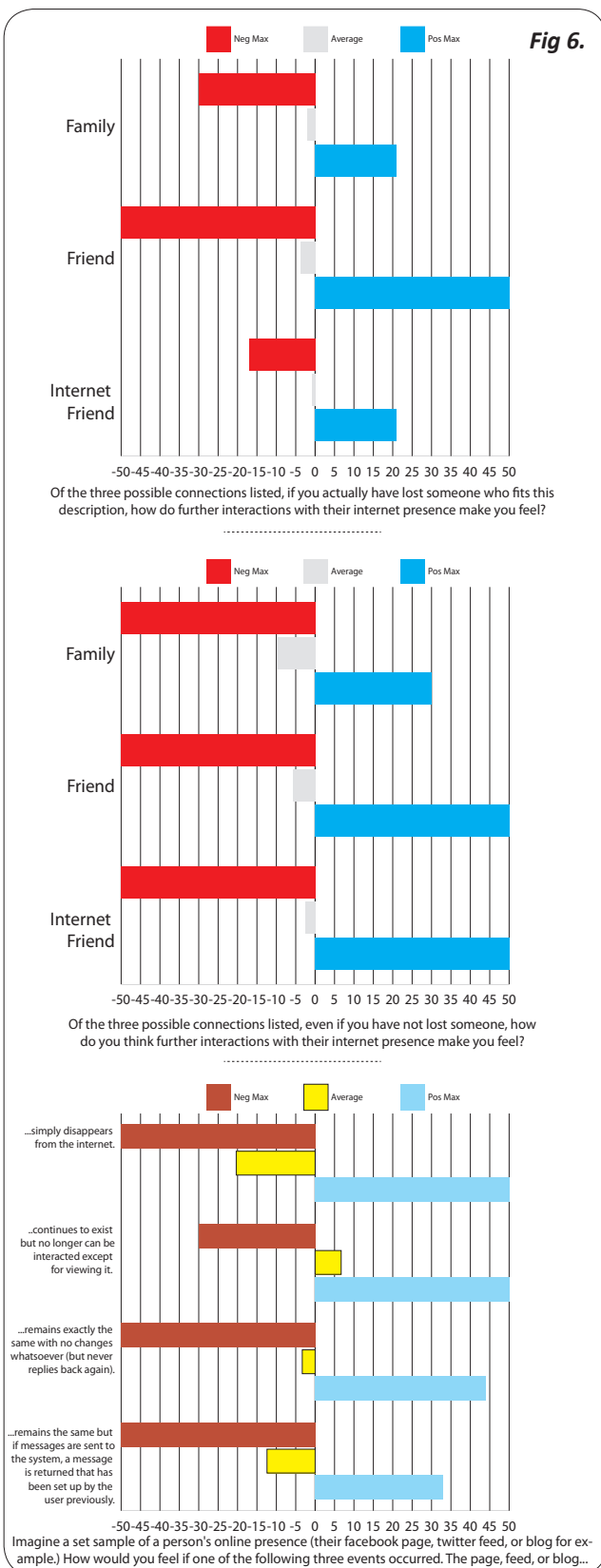
- *Lost a friend on IRC, way back. His PC was still on for a few days and his client stayed connected, even as his friends came into the channel to explain. Many of us directly addressed his "ghost" presence and told stories, apologized for wrongs, et cetera, even though we knew the messages were going nowhere.*
- *Reviewing old postings on my Facebook wall (going way back a couple of years), I see messages from my mother and they make me smile.*
- *I looked at the group that was created in her memory and all of her really close friends had posted great/funny/beautiful memories of her.*
- *Looking at photos of him was incredibly comforting; it was a connection to him I wouldn't have had otherwise, bc I don't have photos of my own.*
- *A Friend from university passed away in 2010; his Facebook page was 'memorialized' and friends and family have continued to post on his wall.*

A similar question was asked about the users negative experiences. Some of these were rather disturbing:

- *She was in a Yahoo ad that ran for about two weeks after she died.*
- *I get very uncomfortable when Facebook tells me that I haven't talked to Scott in a while and I should reconnect.*
- *People who didn't realize what had happened posting "hey where have you been, I haven't seen you around" type of things on their walls.*
- *I found a photo of them that was not previously tagged and felt bad that I could not share it with their family over Facebook now that they no longer have an account.*
- *Facebook suggested I send my father a message. This was after I had tried, unsuccessfully, to memorialize his account.*
- *Their last status says something to the tune of "XYZ can go and fuck off and die." They were in a bad mood that day. This was out of character for them and it's not the impression that I would want to have people remember them by.*
- *A few months after he died, someone logged into his Gchat, and it had his usual busy status, which says "Aweigh", and for some reason it crushed me and I had to leave the office for a bit.*

A general theme seemed to be that electronic mediums allowed users to remember the positive actions of their loved ones better. At times electronic ghosts allowed them to 'speak' to their deceased love ones and find closure. Conversely, a number of systems produced negative ghosts that created the facsimile of life, reminding the users of the reality of the situation.

Finding #5 - Memorial systems put into place allow users to find closure with the deceased. False appearances of life though cause alarm and negative feelings when not expected.



The last part of the survey dealt with inquiring on people's general feelings on the current actions of some social networking websites, when dealing with the deceased, and in general how they felt about encountering their friends and family members on these sites. The answers ranged fairly widely but in general there appeared to be a slight trend towards negative feelings when encountering reminders of their deceased love ones.

When asked about actions the remaining electronic sites could perform, most users appeared to trend towards wanting simple memorial websites. Responses from the deceased were viewed slightly more negatively, and a complete disappearance of the site was viewed more harshly.

Finding #6 - There a slight trend towards negative feelings in regards to encountering electronic reminders of deceased loved ones but at the same time a complete disappearance was not desired.

Interviews The interview process primarily was beneficial for providing support to the findings discovered in the survey.

The first interviewee's loss related to a brother of a close friend. He was not quite as well acquainted with the deceased and primarily interacted with him through the primary friend. This example was notable because the death was more of a lingering event, dealing with a death caused by cancer. Numerous photos and posting on Facebook existed leading up to the final death, showing the brother in the hospital. During the interview it was mentioned how negatively this made the interviewee feel, in that he would have preferred to view the deceased at their best.

Finding #7 - With more lingering deaths, social media creates a record of aspects of a person's life that may not be the most positive moments of their life.

The second interviewee lost a more direct family member, a cousin. This example was notable in a recording of the death that occurred and the resulting social issues that occurred among those left behind. The death in this instance was a car crash, in which the crash was recorded by a viewer on their iPhone and placed on YouTube. This was discovered by the family members before everyone fully knew what had occurred. Many of them saw the accident and viewed the full death. Generally when someone dies, their

final moments are private and not fully shared. In the modern internet age though, more and more people have seen the actual moment of death of others.

A survivor in the crash was also related to the family. He went on to recover fully, but comments he made on Facebook caused a rift in the family. It was viewed that he did not fully appreciate the fact he had survived and blame was placed upon him for the death. Many of the thoughts he expressed may not have been made if this had been a more real-world forum and much of the negative emotions were probably misplaced, as full-emotion can not be expressed via simple text messages.

Finding #8 - Internet media brings to the forefront moments in a persons death that may not otherwise be seen, but also create a wall between the emotions actually felt and the expressions provided by those left behind.

The dealt with a loss of a previous boyfriend by the interviewee and two other connected friends from a more harsh period in their life. They'd had a negative time period with the boyfriend and were no longer 'friends' with them on Facebook when the death occurred. This resulted in them not being able to take part in the online memorials created for the boyfriend and then being left with only the previous remaining texts and messages, pondering whether any of their last words may have had an affect on the deceased, causing their death.

Beyond this, they had other friends who they had grown more disconnected with who died. They only found out about these deaths due to other friends on Facebook informing them. The interviewee commented on the fact that this information wasn't exactly desired. While these people had been friends a while ago, there was a disconnect now. Before the age of immediate information, they might never have heard about the deaths and thusly not have had to deal with the negative emotions involved.

Finding #9 - Social Media is a very short-term based networking medium. It does not accurately reflect long-term emotional connections so on one side it may not allow for the proper mourning connections when they're needed and on the other hand may connect people to deaths they no longer need to know about.

Recommendations

Finding #1 - Currently, not as many users of social media websites have experienced the impact of death upon their electronic communication as expected. This is likely to change though as the active population ages with time.

Recommendation #1 - Determine the expected longevity of the company and create an intended plan based upon this age. Its a reality that not all companies last, so for many, thinking about death is unrequired. Companies such as Google or Facebook though, which appear to be planning on lasting through generations will have to develop a plan for when users die.

Finding #2 - While memorials to family members and distant friends seem to have a neutral or positive impact, the remnants from friends appear to be less controlled, resulting in more negative or morbid remaining connections left online.

Recommendation #2 - For whatever system that is developed, tiers need to be planned for. While later recommendations say that totally removing a person's internet presence is viewed negatively, this may not be true for less connected acquaintances. A users connections should be viewed in tiers and specific actions should be performed for each group; memorials, direct messages, or complete removal from the networking site.

Finding #3 - Regardless of positive or negative, online encounters with electronic remnants were primarily on a monthly basis and mostly took the form of images or written work.

Recommendation #3 - From my own personal experience I saw that physical pictures at a funeral were a primary source of memories and connections. A plan for the deceased on a social networking website should primarily look into creating positive visuals of the deceased and allowing comments to be made on the users wall. This could be used to develop a plan for how a Facebook profile's layout could change when a user passes or the extent to how much other users can comment. There should also be a plan for how to implement the large numbers of electronic photos into a physical for the final funeral viewings. This could either mean a quick and easy way to print off most of a users Facebook picture library or potentially a service that rents out large screens for the viewing of a users account during a funeral.

Finding #4 - Electronic presences have a slightly higher impact on reminding people of their deceased loved ones, and appear to mildly prolong the mourning process.

Recommendation #4 - This is especially important to think of when the mourning process appears to be having a negative impact on those who are surviving. This appears to support a hypothesis I initially started the paper with, in which I have viewed friends and relatives who appear to have unhealthy connections to the deceased within their social media usages. While companies running these sites may not have any control, those connected to the deceased should keep a close watch on those who are still living and potentially create their own blocks of electronic media forms for the benefit of those who survive.

Finding #5 - Memorial systems put into place allow users to find closure with the deceased. False appearances of life though cause alarm and negative feelings when not expected.

Recommendation #5 - Facebook currently has a fairly healthy set of options for the deceased. Users can either elect to leave the profile alone, fully delete it, or turn it into a memorial page. With the latter, the user is less likely to turn up in searches, no longer appears as a recommendation to become a contact, and generally does not appear in as many prompted interaction events. Within other electronic systems, it is of key importance not to display false life. Ads that use users faces, chat systems that automatically log users in, or living users using the deceased profiles should all be prevented, so as not to cause pain to other users.

Finding #6 - There was a slight trend towards negative feelings in regards to encountering electronic reminders of deceased loved ones but at the same time a complete disappearance was not desired.

Recommendation #6 - Generally, try not to simply delete a users profile. While at times this may seem appropriate it is generally better to provide some sort of explanation of what has occurred. This could become a problem as time progresses and the number of deceased users on a site surpasses those who are living.

Finding #7 - With more lingering deaths, social media creates a record of aspects of

a person's life that may not be the most positive moments of their life.

Recommendation #7 - When a user dies either a lingering death or a particularly violent one, care should be taken to remove the more negative images and messages that occur near the end. The memorial pages that are left behind should show the user in the most positive light possible.

Finding #8 - Internet media brings to the forefront moments in a persons death that may not otherwise be seen, but also create a wall between the emotions actually felt and the expressions provided by those left behind.

Recommendation #8 - We live in an age in which more and more people view experiences that were previously only seen by medical staff or emergency workers. Sites such as Youtube or Vimeo may need to create rules in regards to whether particularly violent events that result in someone's death are actually viewable to the wide public.

Finding #9 - Social Media is a very short-term based networking medium. It does not accurately reflect long-term emotional connections so on one side it may not allow for the proper mourning connections when they're needed and on the other hand may connect people to deaths they no longer need to know about.

Recommendation #9 - Social Media and other electronic communication websites need to take into consideration the long-term connections of a user. While immediate fights may cause people to unfriend/block each other, deaths often rise above these short-term issues. Short-term blocks and unfriending should have an option for the living to override, so they can also take part in the mourning (even major real-world fights usually don't prevent the living from attending funerals, but currently websites may prevent proper mourning if even a minor short-term dramatic issue has occurred.

Discussion The recommendations listed are meant as more generalizations for approaches social media and other electronic communication forms can take when dealing with death. Nine recommendations were created but there are some general concepts that appear in all of them.

- Websites need to consider how long they realistically plan on existing, and what tiers of death they may encounter (violent acts, suicides, long-term illnesses, or age related for example).

- The amount of information users create in relation to their death needs to be controlled. Overall there appears to be too much being shared and filters may be desired to place the deceased in the best light possible, similar to what occurs via a funeral home.

- We do not always want to know. Most social media websites are still young, but plans will need to be made as more and more of the users become deceased.

Conclusion What happens when more than half your Facebook friend are deceased. Social media websites and electronic communication have become a very important component of the mourning process, allowing use to inform others of someone's untimely demise and view their best aspects. As we grow more physically disconnected as a world culture social media often becomes the quickest way to inform the widest number of people.

At the same time this information is not always desired. There was a time when if someone's vague highschool friend from twenty years ago died, they'd never know about it. Now, every death is a funeral for everyone they're connected to, a reminder of our own mortality. On a purely informational and work based model this is beneficial, as we do not run into odd occurrences of inquiring on someone who is deceased since we already have the knowledge. Emotionally though it can be drawing. Many of the survey members displayed a slight trend to feeling negatively when encountering this information.

Most of all, these various communication forms need to not prevent proper mourning. A users primary friends on Facebook or short-term block may not reflect their true long-term connections to people. A devoted family member, who is simply not a user of Facebook, might desire to take part in an on-line memorial, without being forced to take part in the overall company.

These are all questions that are not necessarily a huge impact yet. Many of the respondents had not experienced a social-media connected death, but this is only a matter of time. More and more of these will be experienced as our time with the internet progresses.

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Appendices

Appendix A: Survey Questions 1

Qualtrics Survey Software

<https://new.qualtrics.com/ControlPanel/PopUp.php?PopType=SurveyPri...>

Default Question Block

The following set of questions deal with the death and remaining internet presence of people you've known.

If you are not comfortable answering these questions or they bring up too many painful memories feel free to bypass the survey, though it will be thinking about those who have the most pertinent connection in your life that will make the survey the most beneficial.

Answers to the survey will be used in a School of Information report, but your individual answers are private and will not be disclosed. Quotes asked for in the survey may be used, but will not be connected to the answering party.

How old are you?

With what gender do you identify?

With what organization do you most readily identify?

- School of Information
- School of Architecture
- All Hands Active
- i3 Detroit
- LUG
- PFRC
- Michigan Tech
- Other

How web-connected do you consider yourself?
(1 being you barely check your email once a month,
10 being you are never separated from a web-device even when you sleep.)

- | | | | | | | | | | |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Which of these social media sites have you taken part with?

- Facebook
- GooglePlus
- Twitter
- Myspace
- LinkedIn
- DeviantArt
- Livejournal
- Orkut
- Pinterest

Appendix A: Survey Questions 2

Qualtrics Survey Software

<https://new.qualtrics.com/ControlPanel/PopUp.php?PopType=SurveyPri...>

On the social networking site you most commonly use, approximately how many connections do you have?

- 1-50
- 50-150
- 150-250
- 250-500
- 500-1000
- 1000-1500
- 1500+

Have you experienced a death of somebody you know via one of these social networking sites? (This can be a family member, friend, or even vague acquaintance. Please do not count celebrities, politicians, movie stars, etc. unless you had a direct connection to them.)

- Yes
- No

The following set of questions use the phrase social-networking. By this, it is simply meant any form of communication you have that is aided by the internet and is meant very loosely. Emails, voicemails, facebook, myspace, IRC, websites, or blogs count, as long as these are electronic reminders of a deceased person's presence.

Have you lost an **immediate family member** who you had contact with via a social networking site?

- Yes
- No

Please describe who this was and how you interacted with them via the social networking site?

Now that this family member has passed, can you describe any remaining social media presence they have on the internet and any interaction you have with this presence.

Have you lost a **more distant friend, but one you still knew in person**, who you had contact with via a social networking site?

- Yes
- No

Please describe who this was and how you interacted with them via the social networking site?

Now that this friend has passed, can you describe any remaining social media presence they have on the internet and any interaction you have with this presence.

Appendix A: Survey Questions 3

Have you lost a friend, but one whom you had no physical interaction with and you only knew online, who you had contact with via a social networking site?

- Yes
- No

Please describe who this was and how you interacted with them via the social networking site?

Now that this internet friend has passed, can you describe any remaining social media presence they have on the internet and any interaction you have with this presence.

How often do you encounter the internet presence of a deceased friend or family member in the form of an image?

- Never
- Less than Once a Month
- Once a Month
- 2-3 Times a Month
- Once a Week
- 2-3 Times a Week
- Daily

How often do you encounter the internet presence of a deceased friend or family member in an audio form?

- Never
- Less than Once a Month
- Once a Month
- 2-3 Times a Month
- Once a Week
- 2-3 Times a Week
- Daily

How often do you encounter the internet presence of a deceased friend or family member in the form of texts, pokes, or other written forms?

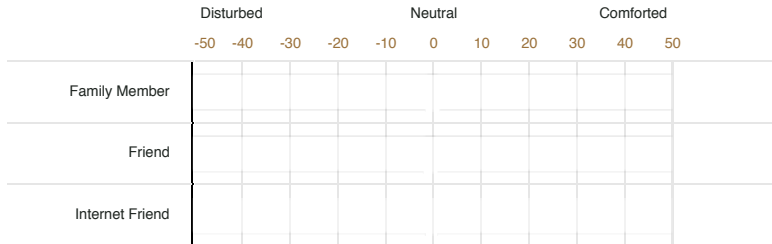
- Never
- Less than Once a Month
- Once a Month
- 2-3 Times a Month
- Once a Week
- 2-3 Times a Week
- Daily

Do you feel you encounter reminders of deceased loved ones more often or less often online than in real-life?

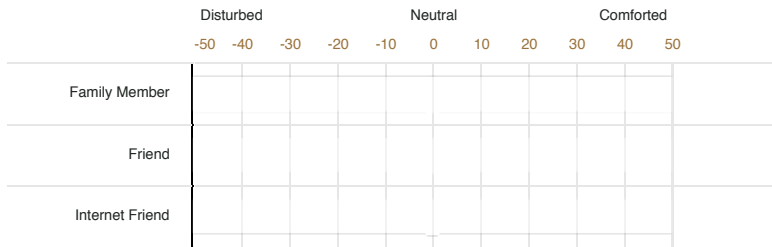
- More often online
- Equally
- More often in real-life

Appendix A: Survey Questions 4

Of the three possible connections listed, if you actually have lost someone who fits this description, how do further interactions with their internet presence make you feel?



Of the three possible connections listed, even if you have not lost someone, how do you think further interactions with their internet presence make you feel?



If you have lost someone, please describe the most **positive** internet encounter you've had with them after they have died (ex.: an automated email, voicemail, facebook page, myspace page, etc.) Please be as explicit as you are willing and describe the encounter in detail.

If you have lost someone, please describe the most **negative** internet encounter you've had with them after they have died (ex.: an automated email, voicemail, facebook page, myspace page, etc.) Please be as explicit as you are willing and describe the encounter in detail.

In comparison to people you know who have died, who did not have much of an internet presence, how would you compare the length of the mourning process for those who had more of an internet presence?

- Mourned longer for those without an internet presence.
- Mourned for an equal length of time, regardless of internet presence.
- Mourned longer for those with a higher internet presence.

Imagine a set sample of a person's online presence (their facebook page, twitter feed, or blog for example.) How would you feel if one of the following three events occurred. **The page, feed, or blog...**



Appendix A: Survey Questions 5

Qualtrics Survey Software

<https://new.qualtrics.com/ControlPanel/PopUp.php?PopType=SurveyPri...>

	Disturbed				Neutral				Comforted			
	-50	-40	-30	-20	-10	0	10	20	30	40	50	
...simply disappears from the internet.												
... continues to exist but no longer can be interacted except for viewing it.												
...remains exactly the same with no changes whatsoever (but never replies back again).												
...remains the same but if messages are sent to the system a message is returned that has been set up by the user previously (ie: 'I love you' or 'Jon Smith has died.' etc.).												

Do you have any other comments in relation to encountering the internet presence of a friend, family member, or acquaintance? Feel free to provide stories.

Thank you for your help!

Appendix B: Survey Results 1

Initial Report

Last Modified: 03/22/2012

1. How old are you?

Text Response
27
24
26
23
28
36
24
41
26
28
25
23
32
41
23
24
31
26
24
23
32
55
68
37
23
25
26
46
23
33
33
27
34
24
54
34
27
26
29 years
24
21
23
37
29
21
26
24
25

Appendix B: Survey Results 2

32
51
28
20
31
22
30
30
5
36
25
28
28
35
45
24
19
29
32
29
24
54
25
25
42
21
40
25
52

Statistic	Value
Total Responses	77

Appendix B: Survey Results 3

2. With what gender do you identify?









Text Response
M
Male
Male
Female
female
female
female
Male
Female
Mail
female
male
f
F
male
Female
female
Male
female
Male
Male
male
Male
Male
Female
Female
Female
F
Female
Female
male
F
Female
Male
M
trans
Female
Female
Female
female
XX
Female
Female
Female
Male
female
Female
F
Female
M
Male
Male

Appendix B: Survey Results 4

M	
Female	
Male	
male	
4	
Female	
Male	
male	
Female	
Female	
Female	
male	
Woman	
F	
Female	
M	
female	
M	
female	
Female	
male	
Male	
male	
male	
M	
Statistic	Value
Total Responses	77











Appendix B: Survey Results 5

3. With what organization do you most readily identify?

#	Answer	Bar	Response	%
1	School of Information		38	51%
2	School of Architecture		3	4%
3	All Hands Active		4	5%
4	i3 Detroit		10	14%
5	LUG		1	1%
6	PFRC		1	1%
7	Michigan Tech		6	8%
8	Other		11	15%
	Total		74	

Statistic	Value
Min Value	1
Max Value	8
Mean	3.20
Variance	7.48
Standard Deviation	2.73
Total Responses	74










4. How web-connected do you consider yourself? (1 being you barely check your email once a month, 10 being you are never separated from a web-device even when you sleep.)

#	Answer	Bar	Response	%
1	1		1	1%
2	2		0	0%
3	3		1	1%
4	4		1	1%
5	5		1	1%
6	6		1	1%
7	7		12	16%
8	8		26	34%
9	9		22	29%
10	10		12	16%
	Total		77	

Statistic	Value
Min Value	1
Max Value	10
Mean	8.17
Variance	2.41
Standard Deviation	1.55
Total Responses	77








Appendix B: Survey Results 6

5. Which of these social media sites have you taken part with?

#	Answer	Bar	Response	%
1	Facebook		74	96%
2	GooglePlus		62	81%
3	Twitter		58	75%
4	Myspace		28	36%
5	LinkedIn		55	71%
6	DeviantArt		8	10%
7	Livejournal		26	34%
8	Orkut		4	5%
9	Pinterest		23	30%

Statistic	Value
Min Value	1
Max Value	9
Total Responses	77

6. On the social networking site you most commonly use, approximately how many connections do you have?

#	Answer	Bar	Response	%
1	1-50		6	8%
2	50-150		10	13%
3	150-250		12	16%
4	250-500		23	30%
5	500-1000		21	27%
6	1000-1500		1	1%
7	1500+		4	5%
	Total		77	

Statistic	Value
Min Value	1
Max Value	7
Mean	3.81
Variance	2.16
Standard Deviation	1.47
Total Responses	77

Appendix B: Survey Results 7

7. Have you experienced a death of somebody you know via one of these social networking sites?(This can be a family member, friend, or even vague acquaintance. Please do not count celebrities, politicians, movie stars, etc. unless you had a direct connection to them.)

#	Answer	Bar	Response	%
1	Yes		55	71%
2	No		22	29%
	Total		77	

Statistic	Value
Min Value	1
Max Value	2
Mean	1.29
Variance	0.21
Standard Deviation	0.45
Total Responses	77

8. Have you lost an immediate family member who you had contact with via a social networking site?

#	Answer	Bar	Response	%
1	Yes		6	15%
2	No		33	85%
	Total		39	

Statistic	Value
Min Value	1
Max Value	2
Mean	1.85
Variance	0.13
Standard Deviation	0.37
Total Responses	39

9. Please describe who this was and how you interacted with them via the social networking site?

Text Response
N/A
My mother - occasional messages sent via Facebook
high school friend's brother
N/A
a very good friend - he had just joined Facebook and passed before we friended each other
Sister-in-law. Talked through email. She had a Facebook profile, but I was not using it much and had not friended her.
N/A
My grandfather would post news updates to our family website - and often comment on our news.
Cousin; Facebook friends
Father, was "friend" on Facebook
Grandmother, we used email and for as long as I could, I would play the last voicemail she left me over and over to hear her voice. I felt terrible when I got a new phone and the voicemail was lost.
3 friends, one avid photographer and poster, others through residual textual postings

Statistic	Value
Total Responses	12

Appendix B: Survey Results 8

10. Now that this family member has passed, can you describe any remaining social media presence they have on the internet and any interaction you have with this presence.

Text Response	
N/A	
None. Her site was taken down and I have experienced no social media presence since her passing.	
It's literally like a shrine to him. People post to him like they are talking to him as if he were alive.	
N/A	
N/A	
his facebook presence is public so I can see everything others post. It is a bit disturbing that Facebook keeps recommended him as a friend.	
Still on Facebook. Can't see her content because not a "friend"	
N/A	
Nothing except when my grandmother posts her news/comments, it's still under his name and not her name so it looks like he is commenting even though we all know it's just Grandma	
Articles written for magazines, obituary announcements, photos	
His profile on Facebook is still active. I had difficulty memorializing the profile. I do not have direct interaction, but do look at it periodically.	
There are few messages that she sent to me at an email address that I still have and accidentally run across or sometimes seek out, I can't seem to delete the messages.	
I just removed all 3 from my account yesterday. 2 account had been inactive since, one was continued by his wife	

Statistic	Value
Total Responses	13

11. Have you lost a more distant friend, but one you still knew in person, who you had contact with via a social networking site?

#	Answer	Bar	Response	%
1	Yes		29	76%
2	No		9	24%
	Total		38	

Statistic	Value
Min Value	1
Max Value	2
Mean	1.24
Variance	0.19
Standard Deviation	0.43
Total Responses	38

Appendix B: Survey Results 9

12. Please describe who this was and how you interacted with them via the social networking site?

Text Response	
We went to High School together, we never spoke online as he was in the military and going through West Point at the same time I was in college, he died in Afghanistan while in the Army	
Coworker and friend, saw person at work frequently.	
childhood friend, kept track of fb status updates and photos	
two childhood friends died a few years apart. one I talked to on a semi-regular basis. the other I mostly followed but did not really talk to.	
Classmate, professional colleague. Communicated via social network rarely, more often f2f	
College friend / roommate. Neither of us were on Facebook much, but checked in every now and then	
The most prominent was a past co-worker. I was friends with her and a few of her friends.	
He was my good friend's younger brother	
A high school friend, someone I had not seen in person in 20-some years but often commented on each other's status and shared FB messages	
one of my childhood best friends, also one of my high school friends	
I was acquainted with these people but did not interact with them much on Facebook--only in person.	
ilya zhitomirskiy. We interacted much more in person, but we chatted and left messages on Facebook and Diaspora.	
A few very close friends from high school passed away in a car accident a few years into college. We actively communicated online, and their accounts are still open.	
This happened twice to me recently, a friend's ex-girlfriend and a friend who was a good friend to many of my friends. I interacted with them only briefly on facebook, more in real life, but we wrote on each others walls occasionally, etc.	
A friend's brother whom I was friends with via facebook.	
In the past year and a half I have lost five Facebook friends whom I knew in person. One was a high-school classmate; three were friends from the community where I lived for 17 years before coming to SI; one I knew from college choir although she was closer friends with my younger sister. With all of them, I interacted occasionally on Facebook via wall posts and messages. I got the initial news about one friend's cancer diagnosis via Facebook. The high-school friend phoned me to tell me about her cancer diagnosis and then added me to a Facebook group of people she had informed, not wanting anyone to learn the news online.	
She was a good friend's girlfriend. She was tagged in a few pictures from a party I had a few years back and she went to my high school.	
A very close friend from my previous graduate degree. We used FB to stay in contact a lot because she lived in Texas so it was a quick easy way to keep in touch.	
A good friend died of pancreatic cancer this January. In addition to face-to-face interactions, we interacted on FB and he had a livejournal blog to keep people informed of his illness.	
A good Friend and Fraternity brother passed away tragically a few months back. We were friends on Facebook, tagged in a few photos together as well. He also uploaded a few videos that I was in.	
Old school friend. Posted and messaged on Facebook and emailed.	
friends that I knew in real life, on social networking sites we kept in touch	
high school classmate in a class of 80 students, but not a close friend	
Former classmate in college has profile on Facebook. Did not interact on Facebook at all. Learned of his death months after the fact, from mutual friend posting on his wall.	
This was a friend. We were connected on MySpace although most of our interactions were in person.	
Friend from high school, just followed her modeling and random things, not much interaction	
Great grandfather- heard through family via Facebook he had passed away	
A few from high school, 2nd hand interactions	
A boy I went to high school with. I used to wish him Happy Birthday online and looked at his pictures when i was bored.	
A friend that I met from being involved in the same music scene. Hung out in-person regularly, chatted on facebook/gchat, commented on eachother FB posts.	
Statistic	Value
Total Responses	30



Appendix B: Survey Results 10

13. Now that this friend has passed, can you describe any remaining social media presence they have on the internet and any interaction you have with this presence.

Text Response	
There is a in Memory of website which leads to a leadership foundation that was started in his name. I look back there from time to time to remember just what kind of man he was. He had honesty, integrity and honor just to name a few. He was a good man, it's sad the world no longer has him around.	
People use his wall as a memorial	
fb page, visit it around the anniversary of her death to leave a memorial message	
Scott still has his Facebook page up. it regularly pops up as common contact and I still write on his page on good birthday. Lisa's presence had pretty much disappeared	
"remembering (name)" fb page.. Look at it occasionally.	
Facebook page is still up. Other people have written goodbyes on it. I haven't yet, but thinking about it.	
Her best friend had her log-in info and had a terrible time dealing with her death; for example, she posted messages under her name describing heaven and how it felt to be dead, telling us all not to worry about her. It was quite morbid, and I can go into more detail if you would like. I "de-friended" her when I was finally done grieving about her death. It felt like a real life step.	
His facebook website is filled with commemorations of his life such as pictures of him enjoying life and posts telling him how much they miss him.	
His FB page is still up. I visit it occasionally, to read thoughts and remembrances from his other friends.	
both friends facebook pages still exist, occasionally I will see that someone has posted on their wall. I occasionally will visit my childhood friend's page to remember him.	
One of them still has a Facebook account. I will occasionally look at their photos but do not interact with them since I know the person will never see it.	
Pictures of Ilya are all over the place.	
Yes - they still have Facebook accounts. Friends and acquaintances use it to post well-wishes and R.I.P. messages on occasion - perhaps most frequently on the anniversary of his death.	
For a while, both friends facebook pages were still active and people were leaving comments about their lives and condolences to their families. Both pages have since been taken down and not been replaced with any memorial groups or anything else to my knowledge.	
Their facebook page is still up and I was curious about who takes care of that page and it's future.	
All of their Facebook pages still exist. I have written messages of remembrance on their walls, particularly around the anniversaries of their deaths or on their birthdays, and have commented on or "liked" things that others have posted. I became Facebook friends with the high-school friend's husband after her diagnosis (possibly when it became clear that her death was near) in order to stay better informed and offer my support.	
Her boyfriend set up a facebook event for her visitation and funeral. He also started a group so that people can write their memories about her on the wall. She just passed a few weeks ago and he still writes things about her in his status.	
a fb group was created as a memorial to her and an additional website was created to go along with it. the fb page is used regularly because we set up a physical memorial for her at my other grad school and a scholarship in her name. It is used as a place for people to connect because most of us are spread across the globe and cannot connect to talk about Lizz in person, thus we share memories and talk over via the fb page.	
His FB site and LJ site are still active. I don't really interact with either, although occasionally I will go to the LJ to see if his partner updated anything.	
It's odd that his Facebook account and Twitter handle still exist. I couldn't bear to look at either after his passing, but many in my circles still "mention" or "@" him in their status updates. I refuse to do so for personal reasons that I believe his spirit should be allowed to rest in peace. Also, I just find it creepy that a deceased person can still have an account months following. Seems there should be sensitivity and concern for the family/friends.	
Profile still on facebook. I have looked at it some since she has been gone.	
their pages have turned into memorials, sometimes people will post i miss you messages	
multiple friends still post "miss you," "RIP," etc. on her Facebook wall every few months and on her birthday	
Facebook profile is still active as far as I know. I posted on his wall when I found out of his passing. Have not posted or visited his profile since.	
I think he still has a Myspace page. I looked it up for a while after he died but haven't checked it in a couple years.	
Part of her RIP group, follow what is going on with a vehicular homicide charge through the group	
They had a facebook site, and it was recently taken down. My fiance is also friends with this person, and just last night mentioned that he saw this IM go online. I think his mom may have his computer now, so she probably didn't realise that that was happening.	
Photos, posts about the individual	
I believe he still has a facebook. I don't look at it.	
I had to block him on Gchat because it was too painful (I think his wife signs on to check emails still). He is reguarly part of facebook's "suggestions", which is similarly upsetting, but I feel weird "unfriending". His name appears online constantly due to his profession (music journalist).	
Statistic	Value
Total Responses	30

Appendix B: Survey Results 11

14. Have you lost a friend, but one whom you had no physical interaction with and you only knew online, who you had contact with via a social networking site?

#	Answer	Bar	Response	%
1	Yes		5	13%
2	No		34	87%
	Total		39	

Statistic	Value
Min Value	1
Max Value	2
Mean	1.87
Variance	0.11
Standard Deviation	0.34
Total Responses	39

15. Please describe who this was and how you interacted with them via the social networking site?

Text Response
He was a kid at my undergraduate institution.
online friend, exchanged messages on Twitter and Facebook
fellow fanfic writer, wrote some fanfic together
N/A
This was a friend of mine from Pennsylvania. We messaged back and forth a lot and became pretty good friends.
Another blogger who died of an overdose.

Statistic	Value
Total Responses	6

16. Now that this internet friend has passed, can you describe any remaining social media presence they have on the internet and any interaction you have with this presence.

Text Response
People post up pics of him having fun in college when he was alive before he got into an accident on spring break in Florida
Some accounts were taken down by his family, but others remain. I don't interact with them.
in memorium posts/fanfics
N/A
The person still has a few social media sites online, with blog posts and pictures still intact.
His xanga is still there. I haven't looked at it in years.

Statistic	Value
Total Responses	6

Appendix B: Survey Results 12

17. How often do you encounter the internet presence of a deceased friend or family member in the form of an image?

#	Answer	Bar	Response	%
1	Never		2	5%
2	Less than Once a Month		19	50%
3	Once a Month		7	18%
4	2-3 Times a Month		7	18%
5	Once a Week		2	5%
6	2-3 Times a Week		1	3%
7	Daily		0	0%
Total			38	

Statistic	Value
Min Value	1
Max Value	6
Mean	2.76
Variance	1.32
Standard Deviation	1.15
Total Responses	38

18. How often do you encounter the internet presence of a deceased friend or family member in an audio form?

#	Answer	Bar	Response	%
1	Never		30	79%
2	Less than Once a Month		7	18%
3	Once a Month		1	3%
4	2-3 Times a Month		0	0%
5	Once a Week		0	0%
6	2-3 Times a Week		0	0%
7	Daily		0	0%
Total			38	

Statistic	Value
Min Value	1
Max Value	3
Mean	1.24
Variance	0.24
Standard Deviation	0.49
Total Responses	38

Appendix B: Survey Results 13

19. How often do you encounter the internet presence of a deceased friend or family member in the form of texts, pokes, or other written forms?

#	Answer	Bar	Response	%
1	Never		16	42%
2	Less than Once a Month		15	39%
3	Once a Month		2	5%
4	2-3 Times a Month		5	13%
5	Once a Week		0	0%
6	2-3 Times a Week		0	0%
7	Daily		0	0%
Total			38	

Statistic	Value
Min Value	1
Max Value	4
Mean	1.89
Variance	1.02
Standard Deviation	1.01
Total Responses	38

20. Do you feel you encounter reminders of deceased loved ones more often or less often online than in real-life?

#	Answer	Bar	Response	%
1	More often online		17	45%
2	Equally		8	21%
3	More often in real-life		13	34%
Total			38	

Statistic	Value
Min Value	1
Max Value	3
Mean	1.89
Variance	0.80
Standard Deviation	0.89
Total Responses	38

21. Of the three possible connections listed, if you actually have lost someone who fits this description, how do further interactions with their internet presence make you feel?

#	Answer	Min Value	Max Value	Average Value	Standard Deviation	Responses
1	Family Member	-30.00	21.00	-2.09	15.16	11
2	Friend	-50.00	50.00	-3.69	24.65	29
3	Internet Friend	-17.00	21.00	-0.75	15.44	8

22. Of the three possible connections listed, even if you have not lost someone, how do you think further interactions with their internet presence make you feel?

#	Answer	Min Value	Max Value	Average Value	Standard Deviation	Responses
1	Family Member	-50.00	30.00	-9.98	21.73	51
2	Friend	-50.00	50.00	-5.66	22.41	47
3	Internet Friend	-50.00	50.00	-2.62	20.92	42

Appendix B: Survey Results 14

23. If you have lost someone, please describe the most positive internet encounter you've had with them after they have died (ex.: an automated email, voicemail, facebook page, myspace page, etc.) Please be as explicit as you are willing and describe the encounter in detail.

Text Response	
	My cousins occasionally post picture of visits to my grandmother's grave. I don't live nearby, so I can't visit her grave, but having it appear in my feed occasionally triggers good memories about her.
	teh news stories about him, links from those who were with him tales of how he affected their lives
	N/A
	fb page to read messages from mutual friends
	the notes left on Scott's page whenever someone thinks of him pop up on my Facebook news feed. they make me think of him and remember him
	The only one I can mention is while intentionally reviewing old postings on my Facebook wall (going way back a couple of years), I see messages from my mother and they make me smile
	Goodbye messages left on wall
	I would say people liking my message of sadness to see them die..and hearing my friend's mom thanking me for keeping her son in my prayers
	I remember discussing another high school friend's passing with my friend who later died. I went back and re-read those FB emails and it was somehow strange and comforting to read his thoughts on death. He wrote about how he hated funerals and open-caskets. It helped explain why his family chose not to have a funeral for him.
	Very nice remembrance posts on facebook from people they knew.
	It's positive to see fb posts about this person
	His Facebook page was converted to a tribute in his honor. It's nice to bump into it and see how many people cared for him.
	Seeing Ilya's photo makes me feel happy to have known him, but also very sad at the same time.
	I do not wish to share - thank-you.
	positive comments from friends and family - none saying anything about their death
	I found the pictures from a friend's memorial posted on her Facebook page to be comforting. I was not able to be present, but seeing the pictures of her family and our mutual friends allowed me to experience it vicariously and made me feel connected.
	I looked at the group that was created in her memory and all of her really close friends had posted great/funny/beautiful memories of her.
	Lost a friend on IRC, way back. His PC was still on for a few days and his client stayed connected, even as his friends came into the channel to explain. Many of us directly addressed his "ghost" presence and told stories, apologized for wrongs, et cetera, even though we knew the messages were going nowhere.
	I haven't really experienced this at all, my interactions are more based on what other people who knew her post about her. She didn't have anything set up to automatically go out if something happened to her.
	His former girlfriend created an album dedicated to him in which she culled many photographs of his friends, family, etc. It was almost like a digital scrapbook where people could see and reflect upon his life. It moved me to tears.
	If your are thinking about them, it is nice to be able to go to their page and see pictures and comments to and from them.
	messages on social networking sites of others who lost the same person
	people connect and form a community around the death; Facebook is the new condolence letter
	Re-reading old emails/saved posts on our family website.
	The most positive encounter I've had was reading the many tributes to that person on many personal and corporate web sites--and none of the major social media sites. The exception was reading the deceased person's Twitter postings which was neither negative nor positive but rather challenging.
	Coming across old photos of us on facebook
	I have none that I can think of.
	Looking at photos of him was incredibly comforting; it was a connection to him I wouldn't have had otherwise, bc I don't have photos of my own.
	I found a message they had written to me, describing how awesome I was and how good of a friend I was and how much they cared about me.
	Having pictures tagged of the person to see them at their happiest moments
	With my grandmother, there are a few emails which make it seem like she is still there sometimes, much like reading an analogue letter does.
	Nothing positive
	Timeline of recorded conversations, exchanges
	When my grandfather passed away, a Chicago newspaper did a story on it. It was nice to see the comment feed and see people gather to share stories. interestingly, I just went back to see if it still existed and while the article does, the "guest book" is gone. Am not entirely dissapointed but it was certianly nice.
	None
	It's never been positive if it was unexpected. If I'm searching though old emails and find messages from him in the search, it can be nice to see our old communication, and I'm prepared to see it.
	Friend from university passed away in 2010, his facebook page was 'memorialized' and friends and family have continued to post on his wallr.
Statistic	Value
Total Responses	37




Appendix B: Survey Results 15

24. If you have lost someone, please describe the most negative internet encounter you've had with them after they have died (ex.: an automated email, voicemail, facebook page, myspace page, etc.) Please be as explicit as you are willing and describe the encounter in detail.

Text Response	
	My family has this strange phrase about letting us have grandm a back from heaven that they post every now and then as a remembrance. It feels strange to see other people be so demanding of someone who only lives in memory now.
	continued pops ups regarding statuses
	Unnecessary drama surrounding him and a girlfriend/other coworkers.
	she was in a yahoo ad that ran for about two weekd after she died.
	I get very uncomfortable when Facebook tells me that I haven't talked to Scott in a while and I should reconnect
	Similar to the note above, while reviewing old Facebook messages (mine or another family member's) I see messages from my mother and seeing her (virtually) as though she were alive is somewhat disturbing, especially when I was not meaning to see her old posts.
	Could also be considered positive, but I thought it was very creepy, but the messages from someone else about how heaven felt like was very disturbing to me, was obvious our alive friend was in need, but she pushed everyone away. I found out later that she had gone into a hospital because she tried to kill herself.
	It just kills me to see pictures of a kid because it constantly reminds me of how terrible it is to see a kid die at 16 and how terrible it is to see many of his pics in the hospital when he should be living as a normal kid.
	Not really after they died, but my last comment to him was a somewhat snarky joke on his status update. It wasn't directed at him yet, in retrospect seemed insensitive. I deleted the comment as soon as I looked at his page post-news of his death. I know it couldn't take back what I said to him, but I did not want a snarky joke on his very last status update. It felt strange to delete something off a dead person's page.
	People who didn't realize what had happened posting "hey where have you been, I haven't seen you around" type of things on their walls.
	I found a photo of them that was not previously tagged and felt bad that I could not share it with their family over Facebook now that they no longer have an account
	However, it's strange to see people have conversations with them, ie today this happened etc
	Seeing Ilya's photo makes me feel happy to have known him, but also very sad at the same time.
	I do not wish to share - thank-you.
	Someone wrote on the wall of a friend who had died something like "How are you these days?" or "What are you up to these days?"--apparently having somehow missed the news. I assume that someone did tell her, but I found it a little disturbing to see the message lingering on my friend's wall.
	For about the first week after she passed, her boyfriend's posts were so full of sorrow it was very difficult to read, even though I wanted to comfort him.
	Two things: (1) the seemingly constant suggestion to friend the person and (2) I am a private greiver and I feel somehow lacking in comparison to those who greive through posts on Facebook.. Like maybe it appears to others his death had not impacted me as much as it really has.
	again nothing automated. NA
	In regards to this individual's twitter account, some sick person created a rogue twitter handle with the intent to mock his death. The name was very dose to his actual name and the person tweeted awful, mean-spirited things about him after his death during the time of mourning. Eventually the tweets began to disappear, though I am not sure if it was because the account was reported or because the person chose to stop. It was extremely insensitive.
	Unless I go looking for them myself, i don't want to get any random info about dead people., such as friend suggestion, etc. Someone i know got a notice that her dead sister had shared a post from my friends Facebook page uesterday. How does that even happen? Creepy.
	none
	automated requests from the service to "reconnect" with person, or ads indicating the deceased "likes" a product
	Suprise at seeing my grandpa's name as the poster - still stops me everytime even though I know it's my grandma now posting.
	Facebook suggested I send my father a message. This was after I had tried, unsuccessfully, to memorialize his account.
	Seeing people talk about his death right after he died. I was grieving and didn't want the constant reminders.
	Their last status says something to the tune of "XYZ can go and fuck off and die," they were in a bad mood that day. This was out of character for them and it's not the impression that I would want to have people remember them by.
	The fact I heard the news via Facebook and not from family directly
	Facebook was the most negative experinece for a friend which passed, he was in a band and many people were posting things that his girlfriend would often read, blaming her for what happened and also, years later mourning his death by posting. There was nothing she or his family could do about it, no one could acces it to make it end, so they finally deleted the profile via facebook.
	spam mail from deceased son
	None
	Being asked to friend a girl I went to high school with who was dead.
	A few months after he died, someone logged into his Gchat, and it had his usual busy status, which says "Aweigh", and for some reason it crushed me and I had to leave the office for a bit.
	none so far.
Statistic	Value
Total Responses	33

Appendix B: Survey Results 16

25. In comparison to people you know who have died, who did not have much of an internet presence, how would you compare the length of the mourning process for those who had more of an internet presence?

#	Answer	Bar	Response	%
1	Mourned longer for those without an internet presence.		7	16%
2	Mourned for an equal length of time, regardless of internet presence.		23	52%
3	Mourned longer for those with a higher internet presence.		14	32%
Total			44	

Statistic	Value
Min Value	1
Max Value	3
Mean	2.16
Variance	0.46
Standard Deviation	0.68
Total Responses	44

26. Imagine a set sample of a person's online presence (their facebook page, twitter feed, or blog for example.) How would you feel if one of the following three events occurred. The page, feed, or blog...

#	Answer	Min Value	Max Value	Average Value	Standard Deviation	Responses
1	...simply disappears from the internet.	-50.00	50.00	-20.34	20.89	47
2	... continues to exist but no longer can be interacted except for viewing it.	-30.00	50.00	6.71	19.53	45
3	...remains exactly the same with no changes whatsoever (but never replies back again).	-50.00	44.00	-3.32	21.35	47
4	...remains the same but if messages are sent to the system a message is returned that has been set up by the user previously (ie: 'I love you' or 'Jon Smith has died.' etc.).	-50.00	33.00	-12.41	24.13	49

Appendix B: Survey Results 17

27. Do you have any other comments in relation to encountering the internet presence of a friend, family member, or acquaintance? Feel free to provide stories.

Text Response
If the profile simply disappears, you forget about the person. If they remain but can only view, then there is only the past. If it remains active and people can share their stories, then the person appears to grow even though they are gone and you feel more connected to the person. If there are automated messages, it creeps me out a little, it's like talking to someone from beyond the grave.
In addition to my friend who passed, my dad died a few years ago and I still like getting email alerts about woodworking magazines he subscribed to.
My mother had very little internet presence, so the effects were not so great. I can only imagine how it would be for someone who had a very large internet process.
I feel like it is a great way to commemorate the life of someone who lived. However, if I look at the page too much, I start to become depressed.
FB used to remind you to write on a person's Wall who hadn't logged in for awhile. I found that disturbing. "Say hi to Alex" It kept nagging me to say hello to a person I barely knew in junior high and who added me on FB and never spoke to me. I heard he died and I actually deleted him from my friend list. I felt kind of guilty, but at least FB stopped nagging me to say hello. Another friend who died (someone I actually knew well), his family had his account deleted after he died. I did not like that, because all of his comments and everything he ever did on FB was just gone in a second. I could no longer go back and read his messages. I could no longer read his last status that said life was good. I think those messages are comforting and should remain online.
Someone I face-book queried once based on information that someone has told me that has a similar condition (perceived personal connection based on diagnosis) attempted to but was not successful thank god. All of this was based on unfortunate events of overhearing someones IRL phone call. I think social networks makes it all worse because it increases ones perception of an increased social connection without a real connection. This causes problems when the emotional regulation of a person has a hard time in which a Freudian slip happens. This leaks out even into real life like that night AHA!... This causes a unfocused train of primary thought because there is a lack of emotional regulation due to recent events.
I find it very strange to encounter ongoing cyber-presence of Ilya.
One of the friends described above had a CaringBridge page set up after her diagnosis—a social networking site not mentioned in your list. The journal (news from her or people close to her) and guestbook had a lot of activity during her three-month battle with cancer. A journal posting was how I learned she had died (although I had visited her in person earlier that day and knew that it was a matter of hours). I continued to check the CaringBridge page for journal updates and guestbook messages after that for probably a few weeks and still look at it now and then (maybe every few months). I find Facebook interactions to be helpful keeping in touch with the surviving spouses and close friends of my friends who have died, whether through the deceased's pages or the survivor's pages. And although this is not what you are asking about, I found both Facebook and CaringBridge to be very helpful during the terminal illnesses of friends who chose to share news in that way. In the case of the college choir friend, her friends held a sort of virtual vigil on Facebook in the 5 or 6 weeks she was dying. (Some friends did not choose to share much or any news on Facebook; in one case I had to get news from mutual friends via phone and email, and in another I didn't know the friend had cancer until after she died. That was upsetting because I never had a chance to say what I would have wanted to say had I known she was dying.)
I think the internet can be a really helpful tool for mourning. It allows so many more people to send comforting messages.
Archived recordings of Dan Kivel's "secrets of the phone guy" talk were reused by a few friends, for "Secrets of the dead phone guy" a few years later. It was hilarious, and reminded us all what a friend we'd lost, but also what a friend we had. Last I checked, his internet presence was still out there, static but reachable. I feel sad for people who die but whose friends aren't technically skilled or committed enough to preserve and maintain their work.
in your question about how further interactions with internet presence make me feel I wish I had been able to provide a more complex answer. I am very comforted by being able to interact with the fb page set up for her, being able to communicate with other people who knew and loved her or just going and looking at images when I miss her. However, I do find it disturbing when something pops up that I have not actively sought out, it usually catches me off guard and I don't like it. I think it is because I when I seek it out I am prepared for the sadness I feel when I think about how much I miss her, but I'm also wanting to remember her in a positive way. But when something just pops up unsought it can be very upsetting and disturbing because I have not prepared myself to deal with it.
I received news on the death of my friend and a first cousin over social media. It was odd to me that those in my life expressed such personal information over an insecure, public medium like that. I also was jolted to see on a glass screen news that personally affected me. That carried into the continued memorializing on the accounts. I think the respective servers, on having evidence of a user's death, should freeze their account and only allow persons to comment on a wall or something. I support the space for a collective mourning process, but there should be a middle ground between mentions and such. I would be equally disturbed if the website completely erased the user's account. Many people blog, journal, and share photos over these sites and those are the only places they have stored these records. Erasing them at will may be well within their legal rights but poses a great danger to the cultural heritage of society.
During a breakup, sometimes I become very preoccupied with checking the ex's internet presences. I'm not sure if this makes it easier or harder to get over the break-up. I'm still trying to figure that out.
A lot of people used the space to write personal messages to the deceased; it helped the family get through it a little.
Not at this time.
It's creepy
This is a great study. My sister died in 1994, before one could easily have a presence on the internet. I think that it would disturb me if there was one. It would feel haunting because cyberspace is a place where things do not die. Bits live for ever and there is a way in which it would feel unnatural. I had an idea once about an application called "in memorium" which would be a vault of sorts where people could submit memories and stories and people could be notified - purely textual, no photos. I envisioned it like a beacon in space or a time capsule for people to find millions of years later.
This happened to a friend-of-friend, but merits mention. He died of drug addiction that started after serving in Afghanistan. His FB page had photos of a respectful military memorial, which was quickly pushed out by a mountain of Farmville posts. It was pretty awful.

Statistic	Value
Total Responses	18

Appendix C: Interview Notes 1

Names have been blanked for confidentiality [REDACTED]

Interviewer 1

The first person that I'll mention is an ex-boyfriend of mine, [REDACTED]. He passed away from a heroin overdose in the fall of 2010, my first semester of graduate school. He and I weren't dating at that time but were still in touch, and actually had a fight on Facebook the week before he passed away. I subsequently found out that he had died via Facebook from his sister, because she didn't have any other contact information (she sent me a message). [REDACTED] and I spoke a lot on the telephone when we were dating--like, hours--and even afterwards, but less frequently. We did a bit of texting, as well, but I would say that the majority of our communication in those last few months took place over Facebook and talking on the phone. I actually was so angry after our fight that I de-friended him, something that I've regretted ever since, as I haven't been able to participate in any sort of memorialization that was going on on his Facebook page. It makes me feel shut off, the fact that I can't go and view his profile, and I've resorted to visiting his MySpace page as well as his "musician" page on Facebook instead. Most of the traces of [REDACTED] that I have left are really online--the videos and music that he posted to MySpace (several songs he wrote for me), the pictures that his mother has posted since his death, the Facebook friendships with his mother/sister/friends. (I do have some of his shirts, cds of his music, etc.) I've tried to go back and find our last conversation/fight in the annals of Facebook, but have thus far been unsuccessful...maybe it's for the best...there's a lot of guilt for me wrapped up in his death, and I think my desire to view our last conversation reflects a sort of effort on my part to try and...I don't know, make it real? Verify for myself that a) I'm a really bad, mean person or b) I didn't really say things awful enough to prompt him to want to die. I think I just want someone to tell me that Yes, I was responsible or No, I was not responsible for his death...but that's not a distinction that anyone on the planet will or can make. (The overdose, by the way, was intentional--he had told a friend that he planned on selling his guitar, buying a lot of dope, and shooting it. Which is exactly what he did.)

Another friend of mine, [REDACTED] that I dated briefly, died of a heroin overdose about a month ago. He had moved to [REDACTED] two years ago and I kind of lost touch with him then, but checked up on how he was doing from time to time on Facebook. I found out that he had died from a mutual friend's 'RIP' Facebook status, after I messaged her to ask what had happened. Turns out he had deleted his Facebook account recently, so I wasn't able to visit his profile page...which sucked...again, the only thing I could find was his MySpace page, which didn't really have much on it, and his obituary.

One of my [REDACTED] also passed away a few weeks ago, again from a drug overdose. I didn't really know her that well--hadn't spoken to her since college--but it's still hard to hear. Again, found out on Facebook, bearer of all bad news...messed a friend to find out what happened, just like with [REDACTED] and read the obituary.

I don't know--sometimes I wonder if it would be better NOT to have Facebook, in this respect. I mean, fifty years ago, if I had graduated college and moved around in the subsequent years as much as I have, I wouldn't have found out about at least one of these deaths, and would thus be un (or at least less) affected. Now, it's like you can see whenever anyone you've ever interacted with dies, which--it just strikes me as very grim. But, on the other hand, who knows when/if I would have found out about [REDACTED] death, if not for Facebook? I'm sure his parents would have eventually found my number in his phone and tried to call me, but who knows?

Appendix C: Interview Notes 2

Interviewer 2

██████ - 17 at the time of passing, we were neighbors when growing up, his older brother was a very good friend when growing up. Friend on facebook, I knew him but not super well. Family of a friend.

Primary SM: Facebook, believes FB was his only social media.

Primary Interactions RW: Go over to your friends place and the brother would be there, wasn't as nice when younger but just an age thing, it happens. He was a nice kid, but a little annoying overly energetic.

Primary Interactions OnLine: Would talk to him every so often. Wall posts and instant messages. Mostly Small Talk.

Death: Longer term- leukemia, lingering. Fairly large number of pictures of him throughout the illness.

Positive: Bench was commemorated, and pictures were put on his facebook as a picture. Combines Electronic and real-world memorial.

People post on his wall after he's died. ████████ believes it still displays his birthday in the reminder section.

Negative: FB has done the "Hey why don't you chat with this guy!"

They also have a community based around him. He has a community and a regular facebook.

Generally people seemed to know, there were not long term lingering affects.

His parents were really glad to see people showing their support on facebook. They actually even printed out a list of the posts and hung it on their wall. They think the facebook may have helped the physical construct of the bench being created.

Long term prospects think about: What happens when half your friends are dead on facebook?

Appendix C: Interview Notes 3

Interview 3

The first true experience where I became aware of the fact was my cousin. Younger, may be two months, like brothers. He lived on the west coast. On christmas eve he was riding with his 18 year old cousin and due to speeding, he may have wrecked due to speeding.

It was the first death in the family, the 18 year old died. Most of the grown-ups had not passed. Good kid. The wreck happened. There was a video of the cars burning, uploaded to youtube.

I was in Cincinnati Ohio for the moment, booked a flight, headed over. The younger brother had a text, that a video was uploaded. This was the first info on what had actually happened. (How fast were they going that the car split in half? Impact, or smoke inhalation.) The video was up for maybe a day before an uncle contacted the guy and asked him to take the video down. That video was a final sort of live moment.

So would you have preferred to see it? Or preferred it never existed in the first place?

"I wanted to see it." Be analytical about what happened. Did something go wrong, could they have saved him. My sister, mom etc. would not have wanted to see it. Funeral on Sunday or Monday, girlfriend shows up.

He was NOT on Facebook. They started a group for him on Facebook as a memorial. He grew up in [REDACTED] Connection only to his brother or his cell phone. He was not available by phone and the brothers shut their phones down.

There was no way for the friends overseas to see what was going on. Indirect way of sharing. Half of the family is still living overseas. His girlfriend still has a few saved voicemails. These were the very last things she could revive in her mind. She texted them to her bf.

Comparitively, my cell phone [REDACTED] does not save voicemails easily.

He thinks she still has it. The voicemail that is. She is still single. I am beginning to forget when it happened. But I got a tattoo to NOT forget. Dec 24th 2009. Parallel to this, the cousin who was 18 was recovering. It was weird, he was the cause for the crash. His siblings were constantly updating their statuses, for friends to pray for him. But no mention of [REDACTED] Though we're very tight, but this caused a mild division. The parents don't engage in the technology. This started to poke [REDACTED] brothers.

They confined themselves to the internet. The boy 18 year old, began to update his Facebook. This caused some problems because there were almost expectations from him since he survived. Finally, the judge sentences the boy for a year in jail (the 18 year old was driving the car). Facebook post, "I want to say goodbye to everyone, I'll be in jail, no more hunting for a year." But he's a kid.

His brother, [REDACTED] brother calls [REDACTED] what do you think. But then the prison sentence got marked down, so now [REDACTED] brothers' okness with the remorse was let down. But it's only the kids, since they're doing the online communication. His sister unfriended me. The parents on one side monitored the kids, the others didn't. Not on Facebook that much. Sometimes they catch [REDACTED] [REDACTED] brothers.

Positive or Negative?: Negative overall. In this situation, I would not have liked to see those status updates. They would not have said this in person. Also, going through my day, I was going through my texts, and all the way down, there were texts from [REDACTED] His name was still on there, it's a fond memory, things were great and good. The texts were positive, good family pictures.

Here's how it maybe came back? First family wedding from the kids. One cousin is getting married. Facebook invite for everyone to come down. Everyone is still mourning the loss. [REDACTED] brother texted, he's not engaging in the celebration. Still done through Facebook.

Appendix C: Interview Notes 4

Two years ago, a friend of mine from college. Was notorious for speeding. Got a facebook update, [REDACTED] passed away from a motorcycle accident. Still hit me but maybe not as much because it had already happened. Didn't surprise, missed opportunity to contact him one last time.

Started up a whole slew of conversations from people from that class since everyone started thinking about how they were contacted. He was not married.

Hadn't contacted him in so long. No electronic ghosts. He wasn't one to update all the time.

A girl in that class, would talk to once a month. committed suicide. Was a surprise. Seemed always happy, and outgoing. Parallel to that life, she's been struggling. Her facebook was very happy.

With the suicide, it was buried rather quickly. They didn't know how to talk about it. We went to the funeral and had our conversations but didn't mention it. Didn't know so you couldn't do anything. For six years, you didn't really know.

Maybe have an electronic will?