

siblingsfor.life

**a master's thesis
by margarita korol**

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Design for Social Innovation
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problem

Context and framing...



This is my brother Eli.

He loved gardening, swimming, being outdoors, doing things with his hands, and hanging out with friends and family.

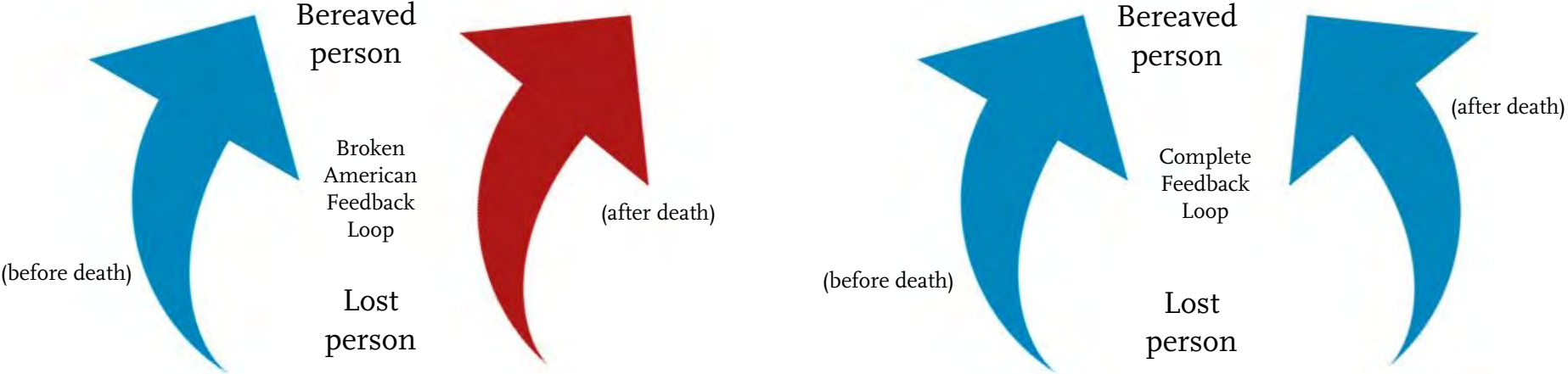
But 5 years ago when he was 14, we lost Eli in a truck collision during a family trip to Yosemite Park. It would be an understatement to say that there are no words, because no words could bring Eli back. It's been rough on everyone, and we've all had to adjust over the years to this new reality that our brother, son, grandson, nephew and friend is no longer here.

I noticed for myself that there really were very few **cultural cues** for how to move forward, especially from the perspective of a sibling. And I knew I couldn't be the only one who's struggling without guidance. That's what got me into this, if I could help myself by finding resources, I could help others too.

cultural cues

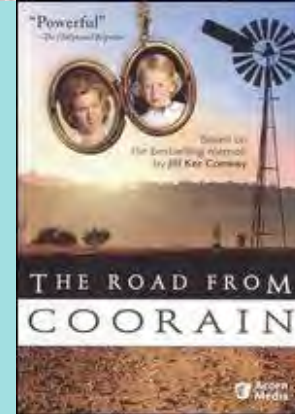
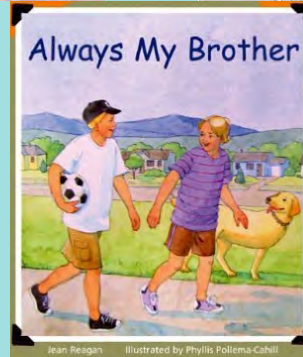
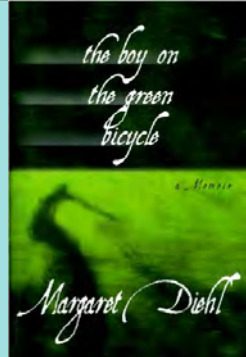
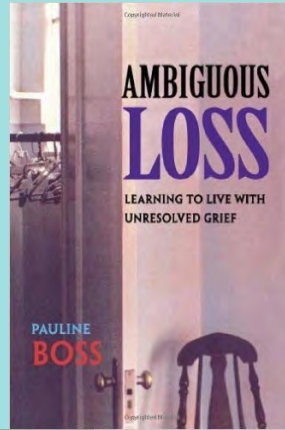
A *New Yorker* article a few years back criticizing Kubler-Ross's stage theory pointed out, "In China, mourners regularly speak to dead ancestors, and one study has shown that the bereaved there suffer less long-term distress than bereaved Americans do."

In America, healing through loss, especially of a sibling, is for the most part dealt with in isolation and without guidance. Americans who lose a sibling often deal with it in isolated grief.



Meanwhile, in places like Mexico (Day of the Dead), or China (where the bereaved regularly consider the perspective of the dead), there is not a trend of prolonged complicated grief.

the state of sibling loss in US



sibling loss in pop culture



“I am so sorry about your sister or brother. How are your poor parents doing?”

“Remember to be good, since your parents are dealing with so much heartache.”

—from *The Empty Room: Understanding Sibling Loss* by Elizabeth DeVita-Raeburn

36 Questions

I wanted to explore popular frameworks that might be useful for connecting people, including 36 questions used for bonding.

“ So the procedure is fairly simple: two strangers take turns asking each other 36 increasingly personal questions and then they stare into each other's eyes without speaking for four minutes. So here are a couple of sample questions:

Number 12: If you could wake up tomorrow having gained any one quality or ability, what would it be?

Number 28: When did you last cry in front of another person? By yourself?...

...The moment you admit to loving someone, you admit to having a lot to lose, and it's true that these questions do provide a mechanism for getting to know someone quickly, which is also a mechanism for being known, And I think

*This is the thing that most of us really want
from love: to be known, to be seen, to be understood.*

*Dr. Arthur Aron first wrote about these questions in this study here in 1997, and here, **the researcher's goal was not to produce romantic love. Instead, they wanted to foster interpersonal closeness among college students, by using what Aron called "sustained, escalating, reciprocal, personalistic self-disclosure."** Sounds romantic, doesn't it? But the study did work. The participants did feel closer after doing it, and several subsequent studies have also used Aron's fast friends protocol as a way to quickly create trust and intimacy between strangers. They've used it between members of the police and members of community, and they've used it between people of opposing political ideologies.*”

—(TEDX talk of the author of [36 Questions that Lead to Love](#), NYT, 2015)

Excerpt from my personal essay in Tablet Magazine on speaking to Harold Kushner about losing my brother (Oct. 4, 2012)

In both books, Kushner explores the circumstances of the biblical character Job, whose faith was tested by God during a series of tragedies that befell him. I saw an important parallel to my own situation: The rabbi who played the “everything happens for a reason” card during Eli’s eulogy was making the same mistake that Job’s friends made when they came to comfort him after God killed his sons; Job’s friends, like this rabbi, might have looked like they were attempting to console Job, but they were actually more interested in defending God.

Kushner argues that when the mourning father cries out, “Why did God do this to me?” he is not actually trying to find out God’s rationale, but rather affirm that he, the mourner, is indeed a good person despite being struck by such a tragedy. At that moment, the mourner does not need God per se; he needs a supportive community to rally around him.

While in *When Bad Things Happen To Good People*, Kushner describes God as limited in his ability to control natural disasters, asserting that God is moral and nature is not, he comes full circle in grappling with God’s limitations as self-imposed: It’s not that God is absent when tragedy strikes, it’s that he is found in strong community and other manifestations of comfort in tragedy’s aftermath. Without anthropomorphizing God as a bearded man in the sky, I suddenly could sense what God was all about. I now could see that it was important to visualize my own image of a perfect universe and what it would look like in this utopia where everyone was a good person providing community and strength to one another. It felt right to pursue God by way of allowing myself be vulnerable among a trusted community, instead of putting all of the burden of the pursuit of the good life on my being a professional rock.

After meeting Kushner and reading his books, I returned to Chicago to be with family and friends, and I felt different. I opened up in such a way that I realized, aside from a short stint in psychotherapy, I really wasn’t talking substantively with those I trusted about what happened to Eli. There was always an urge to make those who wanted to console me feel OK, like a goody bag: Thanks for coming to my pity party, your efforts were not in vain. But being vulnerable is not just OK, it’s necessary, and making efforts to find community one can trust before tragedy hits is crucial for survival after it hits.

Sitting in on a Loss Workshop



I attended a cocreating workshop last week at SVA MFA Products of Design, led by Panisa Khunprasert, whose thesis project involves futuring our consciousness interactions in 2045, when we will potentially be disembodied in avatars, imagining what it would be like to continue relationships with our lost beloved family and friends through technology. Participants represented what the interface might look like and also how the hardware would be kept in your home. Creations and their presentation revealed interesting trends in desires of the participants. An especially interesting trend was the use of mirrors to represent the desire to let the lost beloved have an influence on your life—through harsh advice to see yourself clearly and make adjustments accordingly.

Also, the hublostlove can remain an influencer on your life, since remembering externally is an opportunity to relive/ revive your relationship.

Because given the close nature of this kind of relationship (sibling, family member, close friend), members of the lost love network should know how the hublostlove would react in lots of situations, thereby allowing for visualization of their input at milestones, during life decisions, and in relationships.

1 in 10

I found that it was very common,
and very commonly traumatic.

1 in 10 Americans lose a sibling before the age of 20, and of these, more than 1/3 say that the experience was **the hardest** thing they've ever had to deal with. They also believe their family never recovered from the loss. This same source found that **more support** from family, friends, and coworkers are critical to making the grief more manageable. [[From ComfortZone's study](#)]

the hardest

An early insight was that Losing a sibling can often be categorized as *ambiguous loss*. A second early insight was that our identities are shaped by the context of our siblings.

Sibling Loss Increases Risk of Suicide

Losing a family member is one of the hardest things a person can experience. Many families pull apart and suffer extreme emotional distress after the loss of a child or parent. This is especially true if the loss is sudden and from an accident or suicide. But even anticipated deaths, like those resulting from terminal illnesses such as cancer, can cause immense emotional pain that some people cannot easily overcome.

Although research in this area is extensive, another type of loss that can have similarly negative effects has not been examined nearly enough. When a person loses a sibling, the results can be equally as devastating, and in fact, some believe even more difficult than losing a parent or other family member. Siblings often represent the longest friendship and closest relationship many people have had.

When a sibling dies, the effect can be traumatic and even life-threatening if the death is sudden. People can become easily depressed when they are overwhelmed with grief. These emotions, if not reconciled, can put someone at risk for suicide.

Mikael Rostila of the Centre for Health Equity Studies at Stockholm University in Sweden wanted to see if sibling death resulted in increased suicide in surviving siblings. To assess this, Rostila looked at population data between 1981 and 2002 on over 1.7 million Swedish adults between the ages of 25 and 64.

The analysis revealed that women who lost a sibling were 1.5 times more likely to commit suicide in the two decades following the death than those who did not experience the loss of a sibling. Men were 1.28 times more likely to commit suicide. And if the sibling death was the result of a suicide, the rate increased to 3.19 times for women and 2.44 times more risk for men.

From ComfortZone's study of 1,006 adults was conducted via the Internet between November 24th and December 7th, 2009 by the national polling firm of Mathew Greenwald & Associates, Inc. All respondents were at least 25 years of age. The margin of error for the poll is +/-3.2%. Of the 1,006 adults surveyed, 110 had lost a parent before the age of 20, and 52 had lost a sibling (13 had lost both).

"Grief is a journey. We can't eliminate it, but we can make it more manageable," Hughes said. "More resources and greater public sensitivity to the issue – including support from friends, relatives, classmates, the community, and other caring adults – can make a big difference."

One in Seven Americans Lose a Parent or Sibling Before the Age of 20

Of the 1,006 adults age 25 and over surveyed, more than one in seven (15%) reported losing a parent (11%) or sibling (5%) before turning 20.

Nearly six in 10 (58%) of Americans who lost a parent as a child – and 34% of those who lost a sibling – said that the experience was "the hardest thing (they've) ever had to deal with." One-third of Americans who lost a sibling believe their family never recovered from the loss.

This means that:

1 in 20 Americans lose a sibling by the age of 20.

Of these, more than a third say that the experience was the hardest thing they've ever had to deal with.

A third also believe their family never recovered from the loss.

This same source found that support from family, friends, and coworkers are critical to making the grief more manageable.

MONEY::"Our hope is that this research can help all of us to better understand childhood loss – its incidence, what families are going through, how that loss extends into adulthood and what we can do to ease the grief journey," said Chris Park, president of The New York Life Foundation, which provided financial support for the research.

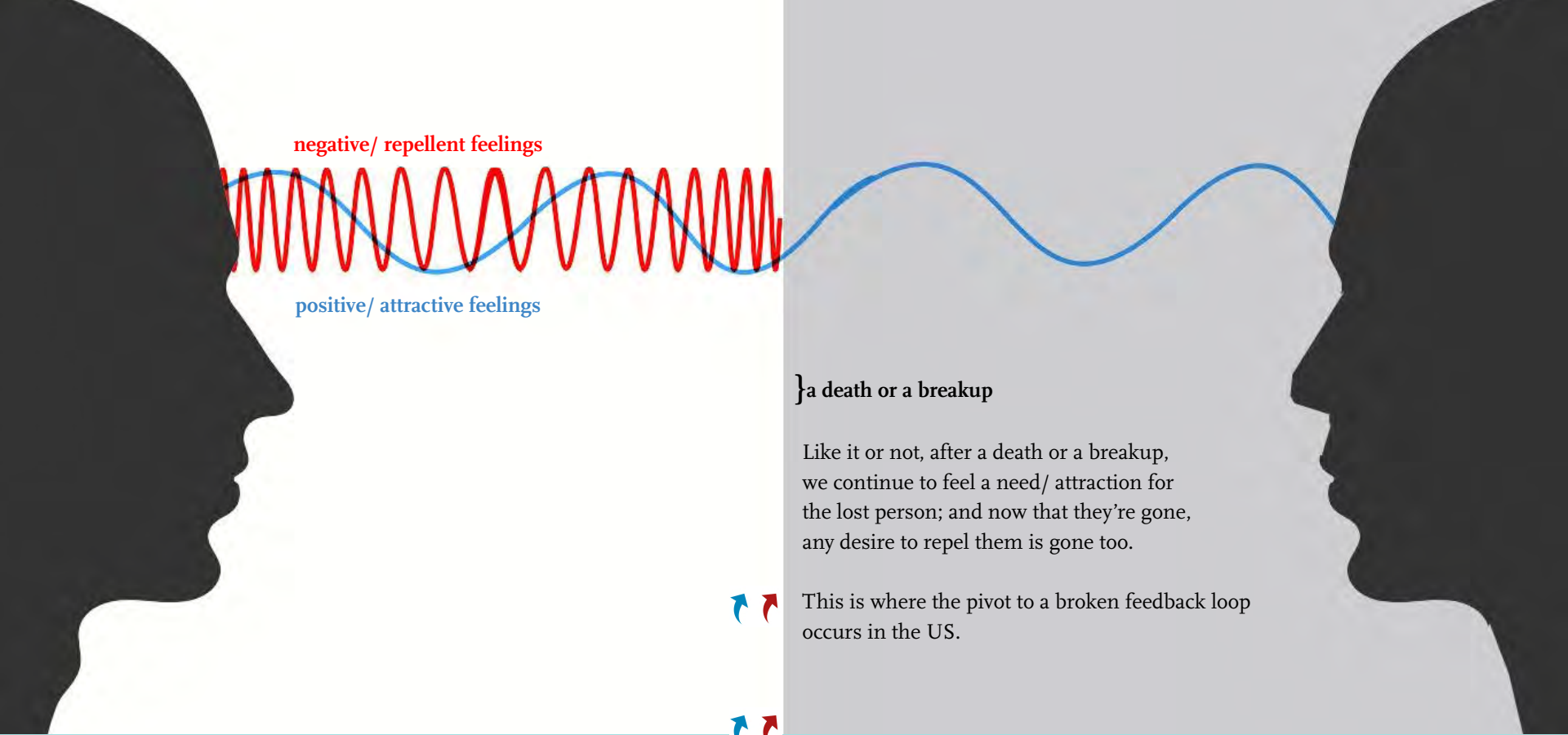
"The burden of childhood loss is immense, and it is a toll paid over decades, not years," said Hughes, who herself lost both parents by the age of 12. "The impact of the experience is disturbingly clear to those of us who have had some exposure to the issue, but it's lost on too many Americans. We need to do a better job of raising awareness of the effects of childhood bereavement so that kids can get back to being kids again – instead of miniature adults. Giving these kids the time and opportunity to heal is critical to their ability to thrive as adults."

Hughes said that kids' grieving process is frequently complicated by feelings of isolation (e.g., "no one else knows what I'm going through") and vulnerability (e.g. "who will be there for me now?") and a wide range of "secondary losses" including moving homes, the return of the surviving parent to work, and financial strains.

"Loss is particularly tough for teenagers, who have to cope with their grief at the same time that they are trying to manage the normal stresses of adolescence and creating their adult identity," said Jill FitzGerald, LCSW, and Founder of the Grief Resource Center of Richmond. "Loss and grief separates them from their peers at a time when most children are desperate to fit in. After experiencing a loss, children need to rebuild their safety nets. We, together, need to support them – at home, at school, and in everyday life."

more support

A third early insight found that an effect of the ambiguity of sibling loss is the absence of sharing in catharsis or externalizing grief.



Isolating in grief + Our national taboos around the dead

No outlet for the absolute need we have to remain connected to a person after they die.

Above framework from *Reaction to an ambivalent object* by Jeroným Klimeš, Ph.D. at Charles University in Prague, Psychology of Relationships.

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process

*Initial approach, research, defined target audience,
prototyping, iterations, successes and failures...*

“I feel like life before my brother died was a dream.”

I started **talking** with other bereaved siblings last fall.

And I could feel palpably the way this traumatic force had shaken up their very identities. A social worker I spoke to told me that the younger you are, the more unexpected—the **more traumatic and life changing**. And that's basically the nature of sibling loss in general, as opposed to different kinds of loss that fit into the natural life cycle.

talking

I asked bereaved siblings, “Can you tell me a story you remember about him or her that makes you laugh?”

Examples of stories . . . and how it feels to share

1. (sister grieving a brother)

“My brother used to wear a mini bottle of Tabasco sauce around his neck as a necklace”

“It makes me happy to remember the ways he was unique, and it reminds me he wanted to savor life-- he liked the aesthetics of it, but he also wanted to always have hot sauce around in case he wanted more flavor in his day”

2. (sister grieving a sister)

“I overheard a conversation with my sister and my niece, her eldest daughter. I remember thinking I want to be a mother like her.

Niece: Mom, I am heartbroken, you think its because I am overweight.

My Sister: My darlyn daughter, you are beautiful, you are smart, you're a lawyer with a bright future, you are health conscious and your working on your weight for you.

I just thought it was brilliant she said all those beautiful positive things.”

“It hurts, I miss her especially now that I am a mother too.”

3. (sister grieving a brother)

“Oo so many stories..my favorite story is of this game.we would lay on the floor in front of each other and connect our feet. We would then begins bicycle motion. We called this game pata LA pata (foot to foot) we thought we invented a cool game and we were entertained for hours.”

“A smile came over my face as I type and then the memories came pouring in.. Can't help hut ask myself if that's the best story I can give...”

Examples of stories . . . and how it feels to share

4. (sister grieving a brother)

“The real memory is getting into the back seat of Brian's big suburban and starting to talk about whatever 14-year-old girl thing we were talking about and suddenly Brian's stereo turns on and his custom-installed bass completely drowned out our ability to hear each other. We listened to Snoop Dogg all the way to the mall, and Sarah was pretty into it. We were laughing a lot but it was genuinely so loud I could feel my organs vibrating in my body. His girlfriend made him turn it down eventually, but I'll just always remember my amazement when it first turned on. He installed the stereo himself, he made a lot of money doing it for other people, too..”

“It feels good,..I've definitely been able to develop more relationship with my older stepsister especially and the family as an adult, and I feel that void where Brian should be for them and for me. ”

Who they've shared stories with and what it was like...

“Both with people who knew him and could appreciate this about him, and also with people who didn't know him as a way to try to describe the kind of person he was. It makes all of us smile and feel connected to him.”

“My mother. We both hurt, but we are both trying to be strong for each other.”

“I haven't really shared it”

“Some friends and they smiled and seemed to feel very warmly about it”

“A few friends who met me after the fact. Girlfriend(s), co-workers, etc. I usually tell it with a smile on my face, so it doesn't seem as sad as it actually feels to tell it. They listen, and understand that it 'must be hard, because I've never lost a parent.' I always respond the same way, "Whatever beef you have with your parents, stop. You need them more now than you did when you were a kid. They will never stop teaching you, no matter how much of an asshole you become."”

more traumatic and life changing

Melissa Wacks, a social worker for students at NYU, who herself lost her sibling, confirmed the traumatic nature of sibling loss due to its being outside the natural life cycle of events, like parent loss. She further explained that while there are some resources for children for grief support, few exist for young adults who have not started their own families beyond their nuclear family. This is significant because more of this person's identity is tied up in this person who is no longer alive, making the adjustment to life after loss even harder to bring to some kind of normal, or to know what normal even is. She quoted a similar number as the doctors working on Complicated Grief Disorder I had spoken to (under Dr. K. Shear), that 6 months to a year out thinking about your lost sibling only in terms of their death signifies maladaptation.

learnings from melissa

Is isolated grief caused by sibling loss PTSD?

Given that it is outside of expected lifecycle events, sibling loss is often a trauma that may create a propensity for post-traumatic stress. therefore, healing by way of behavioral restructuring, as is complicated grief disorder (which is treated as PTSD not depression) could help in digging people out of the helpless place of isolated grief.

the way i tal about it with patients is that i refer to it as a trauma. bc it usually is. the younge ryou are and the more unexpected the more traumatic and life changing. identity change without process but suddenly. if lost brother closer to 50 and had his career and his lfie it would obviously be a humungous thing but i don't know i would experience it quite as traumatically as i did by the age of 24. bc in 40s and 50s people do die of cancer and life stuff. but sudden traumatic car accidnts, and other suddent hings outside of lifecycle are similar to sibling loss at a young age.

What do you think of the 1.5 times higher risk of suicide during two decades following sibling loss?

1.5 times that would make sense if there was a severity of trauma within the lossor if the sibling died by suicide or overdose indicative of mental health

sounds like theory of idenity and need to preserve this person in the active way, see it more as on the plus side of the coping tools. a predictor of someone would do better. instead of what would make them more at risk. pretend that person didn't exist is indicative of the difficulty of integration (identity and emotions–ability to experience).

Have you seen this phenomenon of feeling 2 different universes?

yes it comes up a lot, and she frames therapy this way too. n social work school went to grief group, there's two different lives it's common in a family bc the idea of seeing your family, the pain of grief is that there is a hole in your family. and i think that there's a way for me to see it as a different family than as a family that is missing this key person. loss in the fam can be that way. but i also thihnk that if you're an older person and have grown up and established your own family, the loss of the parent doesn't fele like a hole as it feel developmental. but if you're a young person before marriages and changes like that, it can feel more intensely that way if the sibling loss is for a young person

THEREFORE, THIS IS AN INTERVENTION DESIGNED FOR SIBLING LOSS THAT OCCURS IN 20S AND 30S.

NEXT STEP: Figuring out how to inspire LOLBRO storytelling

And what level of interactivity is necessary for optimal effects.

RANGE OF #LOLBRO INTERACTIVITY

//TELL NO ONE

//TELL A DOG

//TELL A THERAPIST

//POST ON FB AND GET LIKES

//TELL A FRIEND WHO ACKNOWLEDGES THE STORY

//POST ON FB AND GET INTERACTION FROM FRIENDS

//TELL STRANGER WHO GETS TO KNOW U&BRO BY WAY OF THE STORY

//TELL A FRIEND WHO LAUGHS @ WHAT YOU THINK IS FUNNY TOO

//TELL A FRIEND WHO TELLS THE STORY TO SOMEONE ELSE

//THROW A PARTY AROUND #LOLBRO THEME (OR SOMEHOW LET THE STORY DIRECTLY IMPACT YOUR AND OTHERS' EXTERNALIZED EXPERIENCE



**life
before
the
loss**

**life
after
the
loss**

Everyone I spoke with
felt this weird sensation.

It feels like they are now living in an **alternate universe**. As in, there was the universe where he existed, and now we're living living in the universe where he doesn't exist.

alternate universe

I confirmed this phenomenon with all my participants as well as Ms. Wacks regarding her patients, who regularly report feeling this sensation.



“Secret stories that only we shared just evaporate”

Bereavement

A moment that changed me

A moment that changed me - the death of my sister and the grief that followed Emma Dawson

When my 32-year-old sister died of cancer the grief hit me like a freight train

Thursday 3 December 2015 05.45 EST



Shares 16,997
Comments 230



Welcome Margarita Korol, you're signed in to the Guardian using Facebook. [Sign out.](#)

“The secret stories that only we shared just evaporate, because they are too old or too weird to try to explain to anyone else. Every year we wrote the exact same thing in each other’s birthday cards, and howled with laughter each time we opened them, knowing full well what it would say, but there isn’t any card to write now, so that joke just disappears forever...

We will survive, though. Unlike her, we will survive. But we will forever live with a shade of darkness over us. **A grey filter over our world for ever.”**

—Emma Dawson, [The Guardian](#)

I also saw a trend among most (not all) participants that **they weren't really talking about their siblings** much. If the subject of siblings came up, it just felt like an awkward situation where they had to figure out how to disclose that someone had died.

So, it's like they had reoriented to the fact that their sibling had died, but were denying that they had never lived.

they weren't really talking about their siblings

Since the new way they interact with their brothers and sisters is through their deaths, many reported not really talking about their sibling with their family, let alone sharing stories about them with friends or acquaintances. When asked what it feels like to think or talk about their sibling, participants said,

“It hurts, I miss her.”

“I feel that void where Brian should be for them and for me. ”

“I miss him very much and am angered that he isn't still around.”



Melissa Wacks

August 16, 2015 · 🧑

[View on Instagram](#)

👍 Like 💬 Comment ➦ Share

👍 Len Small and 64 others

View 1 more comment



Karen Gerwin ❤️

Like · Reply · 👍 1 · August 16, 2015 at 10:56am



Alyssa Carleton Hanrahan Wow ❤️

Like · Reply · 👍 1 · August 16, 2015 at 11:11am



Axel Tolksdorf This proves a photo can be simultaneously heartwarming and heartbreaking. Thank you for sharing this!

Like · Reply · 👍 2 · August 16, 2015 at 11:11am



Gail Werner Love that picture. Love how it captured such a sweet moment and preserved it forever. Thinking of you and your family.

Like · Reply · 👍 1 · August 16, 2015 at 2:27pm



Leah Jelaine Beautiful ❤️

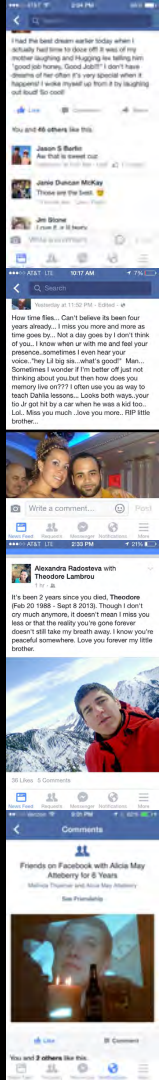
Like · Reply · 👍 1 · August 16, 2015 at 7:06pm



Alison Hoffnagle ❤️ you



Write a comment...



But some people were sharing.

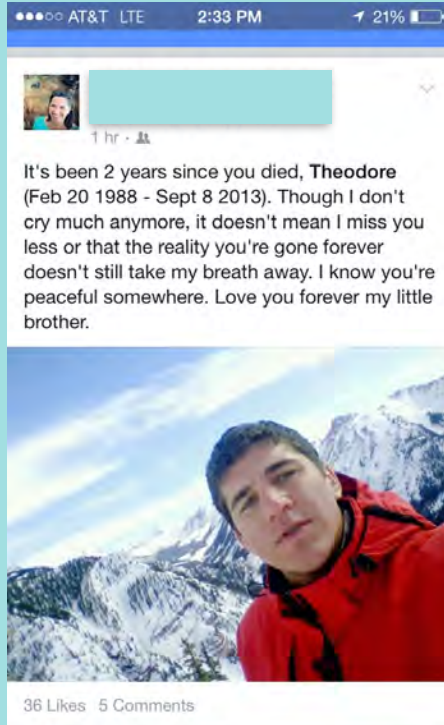
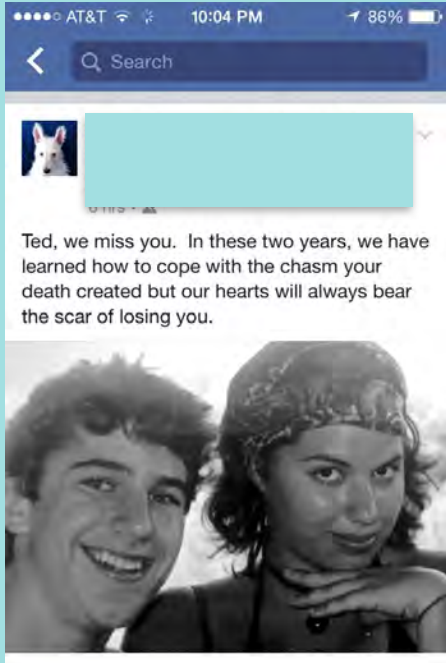
Every so often, usually on birthdays and anniversaries, siblings were **posting photos and memories to their networks**. And it looked to me like this sharing behavior, even in the form of a simple Facebook post, was a rare break from isolated grief where you couldn't help this natural urge to share this very real part of yourself, and to declare to your network that this person existed and mattered to you.

When people engaged in this behavior, they felt less isolated in their grief since it was giving an in for family and friends to offer support to them, which isn't an urge that people generally act on when it comes to sibling loss; they're focused on offering support to parents, spouses and children, but less so to siblings.

My interviews were revealing that moments of sharing like this are very, very rare in the day in the life of a bereaved sibling. It isn't that they don't have stories about their siblings, of course they do. They shared an uncommon bond. But Facebook aside, bereaved siblings aren't recognizing opportunities to share them in their everyday lives.

So I saw room to innovate in that problem space—how could I help create more opportunities to share stories and celebrate life rather than isolating in our grief?

posting photos and memories to their networks



“If you’re taking the time to laugh, you’re doing something unbelievably brave; you are protesting against sorrow by remembering, even if only in small moments, that the world is still good, and there are still things to smile about.”

—J.F. SIETKIEWICZ
Memoirs of a Griever

hypothetical frameworks

In trying to frame these learnings in early stages of the design process, I hypothesized that stories were the link to bringing people more opportunities to connect with the people who were already part of their networks. A big problem being that siblings do not ask for help, and others tend to only offer when asked, these frameworks would help me understand the opportunities for storytelling that could be leveraged.

joyful/ meaningful memory
+ sharing tool

new shared experiences
around your sibling with
your network

★ This cybernetics map illustrates that remembering together would function as feedback on the input loops of your life decisions, milestones, and relationships. The result of which would be to keep this hublostlove “live” in your mind bank, and ultimately let them remain an influence in your life.





LOLBRO storytelling
lets someone new
be impacted by
your brother's light.

There's never
not a shadow,
but you don't
need to stand in



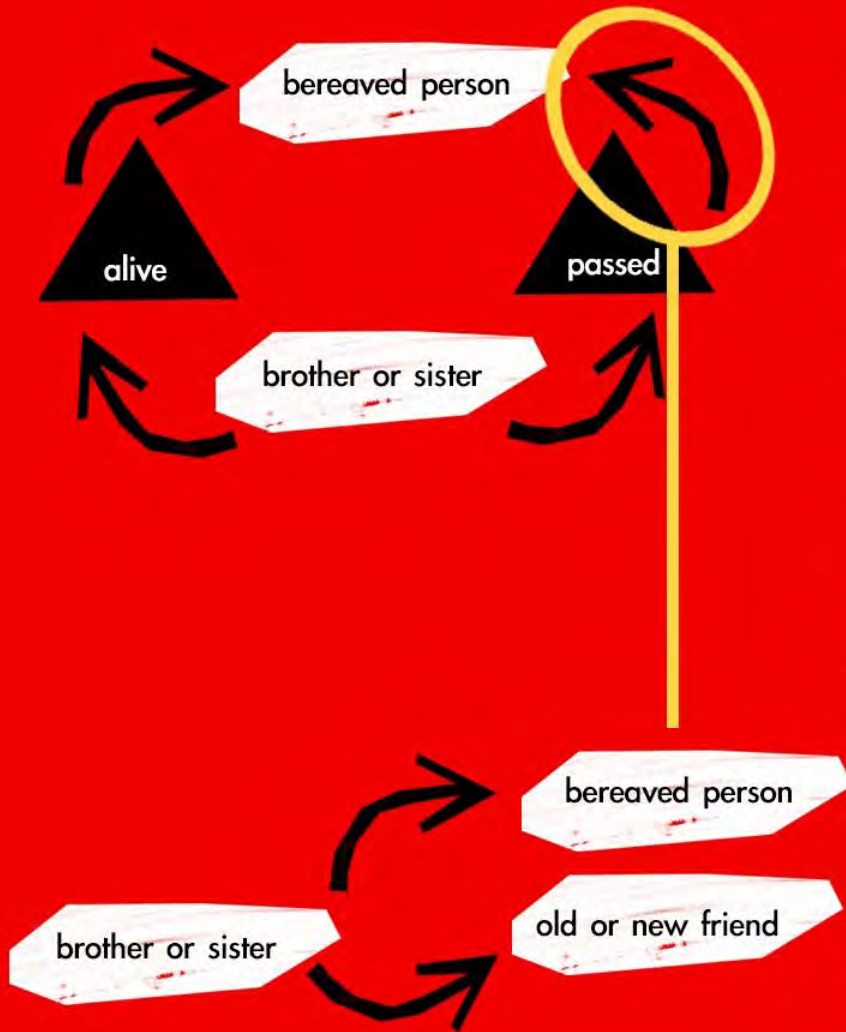
Focusing on his death
isolates.



LOLBRO storytelling, Mexican Catholic, and Chinese relationships with the dead continue to incorporate them into life narratives.



Meanwhile, the conventional American grief myth (based on Freud and Keubler-Ross) requires the bereaved to sever emotional ties from those who have died



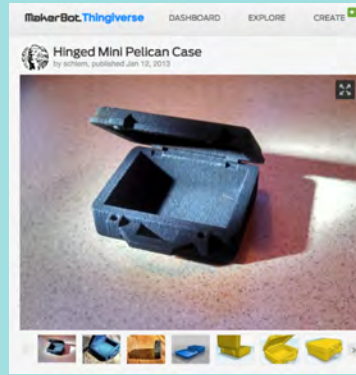
LOLBRO storytelling, or sharing funny stories from a person's life lets a bereaved sibling (as well as the person listening to the story) be newly impacted by the life of her brother, even after his passing.



During an early prototype, I asked four participants to wear a moodring for a week, and every time someone asked them about it, they should use it as an opportunity to share a funny story from their siblings' lives. I wanted to know how it felt to share the stories, what it was like for the other person, and what happened after they shared.

The results showed a positive correlation between sharing stories and feeling less isolated, less disconnected, and more trusting of the person they were talking to. The awkwardness of bringing up their brothers and sisters was replaced by an opportunity to share a major part of their identity that they had been hiding from the world—

They were coming out of the closet as this person's sibling, and it felt good.



early prototype

I had originally 3D designed a conceptual prototype and distributed a survey to collect folks' experiences sharing funny things from the lives of deceased loved ones. This consisted of:

- * I blinged out 3D printed mini pelican case on a chain per participant (later replaced by a mood ring for simplicity's sake)
- * A survey to collect feelings about what it was like to share, what happened next, and if you were able to get feedback from the other person, what was it like for them to hear your funny thing?
- * Making the case for keeping brothers and sisters animated in the lives of bereaved siblings through a surviving oral history

the results

(sister grieving a brother)

“My brother used to wear a mini bottle of Tabasco sauce around his neck as a necklace. It makes me happy to remember the ways he was unique, and it reminds me he wanted to savor life-- he liked the aesthetics of it, but he also wanted to always have hot sauce around in case he wanted more flavor in his day.”

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“Oo so many stories..my favorite story is of this game.we would lay on the floor in front of each other and connect our feet. We would then begins bicycle motion. We called this game pata LA pata (foot to foot) we thought we invented a cool game and we were entertained for hours.”

“A smile came over my face as I type and then the memories came pouring in.. Can't help hut ask myself if that's the best story I can give...”

the results

“Both with people who knew him and could appreciate this about him, and also with people who didn't know him as a way to try to describe the kind of person he was. **It makes all of us smile and feel connected to him.**”

“With my mother. We both hurt, but we are both trying to be strong for each other.”

“I haven't really shared it”

“With some friends, and they smiled and seemed to feel very warmly about it”

“With a few friends who met me after the fact. Girlfriend(s), co-workers, etc. I usually tell it with a smile on my face, so it doesn't seem as sad as it actually feels to tell it. They listen, and understand that it 'must be hard, because I've never lost a parent.' I always respond the same way, "Whatever beef you have with your parents, stop. You need them more now than you did when you were a kid. They will never stop teaching you, no matter how much of an asshole you become."”

**life
before
the
loss**



**life
after
the
loss**

Sharing stories from siblings' lives is a **successful** way to weave the two universes together, the one before the loss and the one after.

successful

I considered several directions for my next explorations, including:

Intervening at the moment of proximity with a friend to insert an opportunity to share a funny thing.

Popularized trigger statement, quiz, Movember-type activity

Modeling the behavior of sharing of funny things with someone.

Fictional story, song, art exhibit, coloring book, allegory, Sesame Street segment, group workshop, therapist script

Engaging in a profound catharsis with others sharing funny things from lives of their siblings.

Collection of stories in a book or YouTube channel, a hashtag, a fraternity, standup comedy, a penpal system, a “giving tree”

Reminding a sibling to focus on a funny thing instead of the loss itself by way of an object that symbolizes it.

Home altar, garden, charm bracelet ritual, BitStrip, drinking game, nostalgic sensory experience, tattoo

Planning activities that celebrate shared interests of the siblings.

Trips, parties, sports, designing an annual ritual

life
before
the
loss

my sibling lived

i'm their sibling

we had some
fun times

life
after
the
loss

Siblings get to embody:

1. He didn't just die, but he also lived. he did exist.
2. They are still this person's sibling.
3. And the fun times they shared did happen.

So my next question was, what's a huge way to get people to really really embody these things? What natural storytelling devices could I leverage that would give these siblings **more opportunities** to practice being the brother or the sister of someone who is still a big part of who they are?

more opportunities

Some siblings were already leveraging Facebook for connecting with networks, and I wanted to both share those options with people not already engaging in that behavior, and also connect people with even more ideas. I looked in the direction that people were already trying to share stories, but for different reasons.



I landed on tattoos.

Readers with tattoos know that, like it or not, people will ask you about the meaning of your tattoos. So, what if the meaning of your tattoo was a happy memory about your sibling that you all of the sudden found yourself sharing and representing yourself with, to your friends, family, and people you were just meeting?

It didn't take much convincing at all to get **four people** to join me in this experiment.



**When you lose a sibling,
it's important to remember that you will always
be the brother or sister of that person,
even through loss.**

Celebrating the life of your sibling helps you do that.

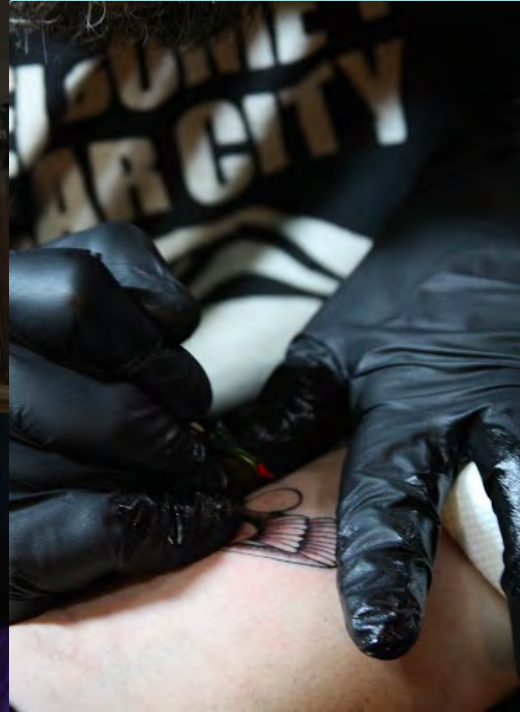
**You are invited to come design a tattoo that celebrates
the sweetness that your sibling brought into this world,
and get tattooed for free.**

February 12 and 13, 2016, my team will be meeting participants
and their trusted friends to design tattoos of favorite stories.

If you are interested in participating, please get in touch.

SVA@NYC Margarita Korol
DSI Masters Candidate, Design for Social Innovation
Design for Social Innovation mkorol@sva.edu

The invitation distributed to participants and their networks online and offline.



What it looked like



This is Grace, and it wasn't her first tattoo commemorating her brother Scott, who died suddenly in a house fire in her Indiana hometown. Two weeks after it happened, she and her other brother Charlie went to get tattoos of his signature. She got it on her arm, and Charlie got his initials inside his lip "so he would never have to drink alone." This is what some of our conversation sounded like: <https://www.youtube.com/watch?v=Uu5nsbhYtIM&feature=youtu.be>)









While the signature allowed Grace to have Scott be a part of her symbolically, it didn't really have a story attached to it so sharing it has been kind of weird for her. But after a week with her new tattoo, she's reporting positive results. Having a funny story attached to your tattoo makes you light up, and especially when you're sharing with someone you don't know well, it gives the person you're talking to an "in," a chance to relate on common ground, which prepares them to be authentic when they learn that this person's sibling is no longer alive.



“I definitely feel more like myself with it and am grateful.”
—Grace



Grace



This is Steve.

And he originally had an idea for a tattoo involving a wolf sleeping near a tombstone. I knew this signified that the way he interacted with the memory of his brother Aaron was very **death-centric**. I encouraged him to think of a fun or funny memory growing up with him and to get back to me and we'd design something around that—because when someone asks him about his tattoo, instead of saying, “My brother died,” he could say, “My brother and I used to...”

He called me back in an hour with a very funny story taking place in a playground so we designed something with a swingset.

“When you asked me to think about getting a tattoo that celebrated him instead, I had to dig for it, but it was always there. And that story was a really good time.” —Steve



Steve



Kristian was another participant who had really been isolating in her grief. I found her and Grace through The Dinner Table's mailing list, an NYC-based organization that organizes potluck dinners for people who've experienced loss. She already had a tattoo inspired by her brother, but the story it elicited was a sad one. For her new tattoo, she got a cool triangle pattern that evokes the music video for a song she remembers screaming the lyrics of together in their hootie. There was a huge contrast in talking about these stories for Steve, Kristian, and actually all the participants versus almost every kind of interaction bringing up their siblings.

“I enjoy looking at it, and it is comforting to have another catalyst to discuss my brother.”

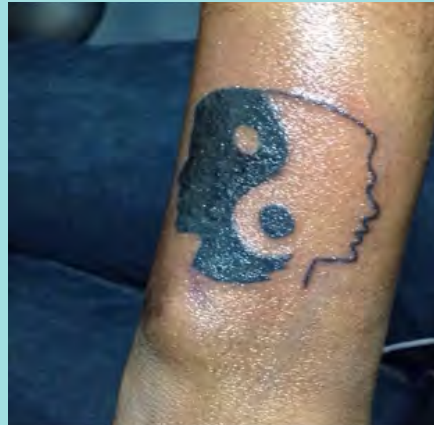
—Kristian

“Knowing that it wasn't going to result in an awkward, uncomfortable look or a halt in the conversation was refreshing.”

—Kristian



Chantell lost her twin sister at birth, but told me that she has always felt like she was half of something. It was a tough one because there were no literal stories to pull from, so the symbolism of the yin yang brings her to a place that calls forth the positive feelings of balance and peace she feels in remembering that she will always be a sister to Chanel.



“I’m just happy I can be one
with my sister, it’s a blessing to have her
as a part of me on my body.”

—Chantell



Chantel

|



Chantel
|



**100%
shared
the
tattoo**

**100%
shared
sibling
story**

**100%
positive
experience**

Surveys I distributed after some time living with the tattoo revealed that everyone had showed their tattoo to someone, and the sibling story came up 100% of the time. And 100% of the time they had a positive experience talking about their lost sibling. That's basically a paradigm shift from the awkwardness usually associated with moments when their siblings were coming up and having to explain that they were dead.

Having a funny story attached to your tattoo opens you up, and especially when you're sharing with someone you don't know well, it gives the person you're talking to an "in," a chance to relate on common ground, which prepares them to be authentic when they learn that this person's sibling is no longer alive.



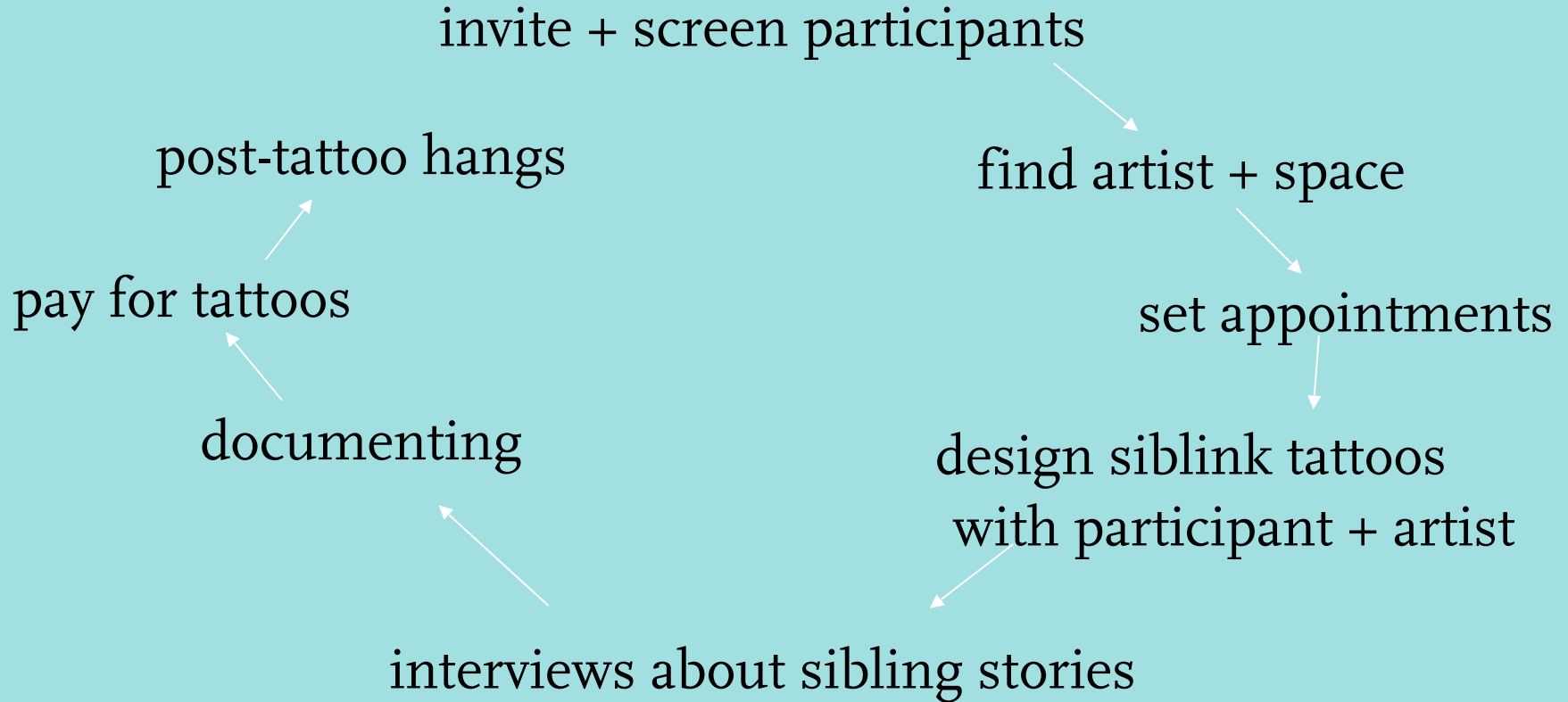
I did have another unexpected insight. This is Grace and her friend who came for moral support. I became good friends with them and all four participants. We were able to be vulnerable with each other because we had gone through this unique trauma so there was less to explain. But also, because we went through a healing ritual **together**.

I knew that I'd have to leverage
this community aspect somehow.

siblingsfor.life

intervention

Intention, user testing, user feedback...



I deconstructed the process of the tattoo pilot in order to identify where my role was most efficient in providing more examples of opportunities for sharing sibling stories. I realized that the invitation to try something was the strongest because I could go beyond this one idea, since tattoos aren't for everybody going through sibling loss.

SIBLINGSFOR.LIFE

So, tattoos work. I suggested it and 4 people thought, “yeah that’s for me.” But tattoos don’t work for everybody who has lost a sibling. I needed my intervention to do what the tattoos did on a larger scale. **Provide more examples of opportunities** to share our siblings’ stories, so we can incorporate them in our everyday lives.

So, what is working for people?

In social innovation, we have this concept of the positive deviant. That is, under circumstances that usually lead to a lot of suffering there are outliers who are having more success than others at adapting.

I landed on the conclusion that my role had to be that of someone who collected and synthesized examples like story tattoos or Facebook sharing for this population.

I needed to build a tool that reminded them that they will, undeniably, be siblings for life.

more examples of opportunities

Since last year, I'd been collecting stories from siblings of how they had been connecting with their sibling identity as well as shared memories.

“We’re going to print a cookbook of his recipes soon, and we keep up his garden in the backyard, which bears delicious fruits and vegetables for our dinners...When we share these memory books with friends, we get to tell stories about him. And it’s like he was there. No, but at least it’s like something new, recent happened (including him).”

—*Karina*

“I like to tell stories to my kids about my brother, especially now as they’re getting older. I want them to know what he was like. Like when they do art projects or play music, I tell them about their uncle and how he was an artist and a musician too.”

—*Melissa*

intention

After many iterations through the process, my final intention going into the final manifestation of my thesis intervention reads as,

Providing bereaved siblings with more examples of everyday opportunities to share our siblings' stories, so we can incorporate them in our everyday lives.

Earlier versions of this were:

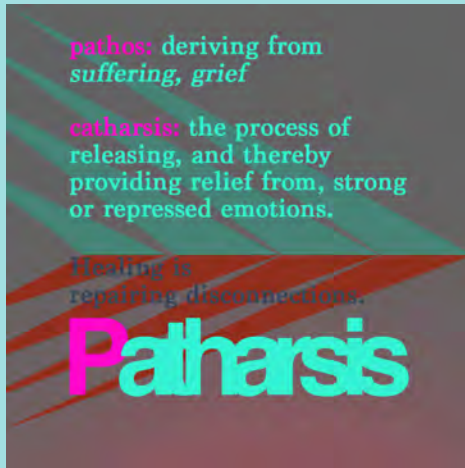
* To design an intervention that helps New Yorkers reconcile their grief, relationships, and identity under this new reality in which their siblings are not alive.

* I am helping people who lost a sibling connect with others over the funny things from their siblings' lives so they can celebrate life together instead of isolating in their grief alone. (And as a designer, my role is to create more opportunities for sharing these stories.)

* My goal is that surviving siblings like Emma want to lift the grey filter from their lives in order to let go in love, in honor of their siblings' lives.

* To design tools that would help folks reconcile their grief, relationships, and identity after the loss of a sibling.

user testing and feedback



#siblingthings
#LOLbro



Earlier iterations of branding were not as simple and intuitive as siblingsfor.life.

jami: share darinda's superwoman moments with brothers and sisters you meet in facebook groups

alicia: stay close with your sisters to keep brian in your life

steve: share an afternoon at the playground with the kids in your life like you did back in the day with your little bro

kristian: whenever you're riding around, take the opportunity to sing as loud as you guys did in his hooptie

mishal: keep using your athletic talents to fundraise on rakan's behalf

julie: encourage margarita to share more stories about eli by saying "i would have liked to have known him"

grace: rock out to blind melon like scott's right there with you

melissa: keep jeff's scholarship going for young artists beginning their careers so he can keep producing art

madelyn: visit your and michelle's mutual friends to bring her back into your lives

diana: play games with your daughter that would make you and your brother laugh

margarita: celebrate siblings with your tribe

alexandra: share more sweet stories about ted with your friends

chantell: tell people about your sister whenever someone

This month, I launched siblingsfor.life

It's an online space to figure out more everyday opportunities to celebrate the lives of siblings we've lost and authentically be known as their brother or sister. **Each post features some advice from a sibling** on how they are finding ways to share stories. And the advice reads, not only as advice to others, but also as a reminder to themselves.

each post features some advice from a sibling

siblingsfor.life

gina: find your siblings' spirits in the beauty around you and celebrate it

siblingsfor.life

steve: share an afternoon at the playground with the kids in your life like you did back in the day with your little bro

chantell: tell people about your sister whenever someone asks what the story is behind your tattoo

for chanel, born december 27, 1993

Chantell, whose twin sister died at birth, had always felt a connection with her all the same. She told me how she had always felt like one half of something, and was excited to externalize that and show it off as who she was. She brought along a beautiful design of a yin yang composed of faces, that Mike the tattoo artist designed into a simple tattoo for her forearm.

Chantell's boyfriend Tre joined, holding her hand through the tattoo process.

Since getting the tattoo, countless people in her life ask about her new tattoo. She reports loving the opportunity to share this special relationship she still shares, a unique twin bond that is still part of her identity. While she didn't have a chance to experience stories with her twin Chanel beyond sharing the womb, she says, "I'm just happy I can be one with my sister, it's a blessing to have her as part of me on my body."

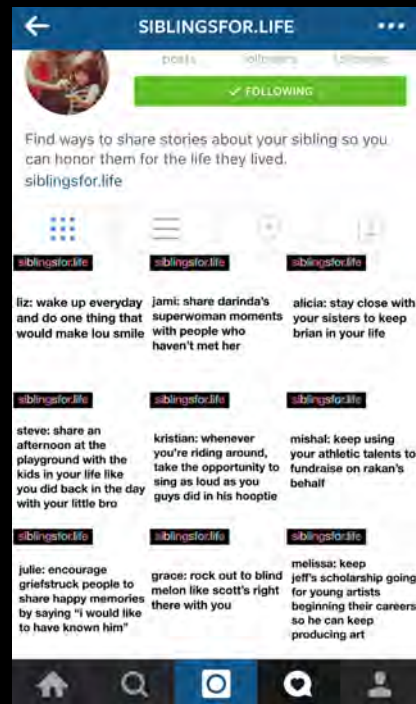
0 Comments

Sort by Newest



Add a comment...

Facebook Comments Plugin



The post itself has the name of the sibling, their birthday, and **how they share stories**.
Facebook interaction is also leveraged via commenting.

siblingsfor.life

your sibling's legacy here.



siblingsfor.life
Health/Wellness Website



Learn More | Liked | Message | ...

Timeline | About | Photos | Likes | More ▾

Search for posts on this Page

- 349 likes +347 this week
Nicole Malcolm and 15 other friends
- 87 post reach this week
- See Pages Feed
Posts from Pages you've liked as your Page
- Invite friends to like this Page
- View Promotions

ABOUT

- Find ways to share stories about your sibling so you can honor them for the life they lived.
- <http://siblingsfor.life/> [Promote Website](#)

PAGE TIPS

- How to Create Effective Posts**
Short, visual posts created for the right audience are more successful.
- Add Page Roles**
Give someone an admin role on this Page so you'll have help managing it.
- Try Posting a Short Video**
Videos help engage people in News Feed and on your Page.

See All Page Tips

PHOTOS



Status | Photo / Video | Event, Milestone +

Write something...

siblingsfor.life
April 22 at 9:17pm · 🌐

Read Liz's story at <http://siblingsfor.life/post/143242022529/>
"Every day I wake up and do at least one thing, in his memory. Forever keeping him a part of my daily life. Whether it is waking up and having his favorite cup of coffee, walking in the park or visiting with his daughter."



liz: wake up everyday and do one thing that would make lou smile

40 people reached [Boost Post](#)

Like | Comment | Share

Chronological

siblingsfor.life · 🌐

An associated Facebook page incorporates that strength of community revealed in the tattoo pilot, and let's the posts integrate into their newsfeed each day, **making this paradigm shift a part of their daily consciousness.**

making this paradigm shift a part of their daily consciousness

Both a Facebook page and group have been set up, but the page is proving to be more inviting to interaction. In addition, an Instagram feed compiles posts similar to the website, to be strategically leveraged for audiences that prefer that platform in the future.

siblingsfor.life

learnings

Conclusions from it all...



VISITOR POSTS

- Mira Preston**
Yesterday at 5:22pm
I hope it's okay if I write something here. I was 14 and my big brot... See More
Like · Comment
- Shauna Robinson**
April 9 at 11:30am
This Tuesday will mark the 23yr anniversary of my brothers murder. H... See More
9 Likes · 3 Comments
Like · Comment
- Steven Espinoza**
April 5 at 2:04pm

PEOPLE ALSO LIKE

- Twice Blessed: ...**
Community Like
- Crock Pot Girl**
Community Like
- Be Inspired Bo...**
Community Like

English (US) · Español · Français (France) · Português (Brasil) · Deutsch · Italiano

View 2 more comments

Sibling Loss Support Group
March 27 at 10:16pm

One of our group members sent us a message that she has lost 2 siblings. She is at a loss on how to cope with this unique situation. I know we have had others with similar situations, if you are one of them or have words of encouragement for her, please comment here. She would love to reach out to some of you for support. ❤️ to you all and I hope you have had a Happy Easter remembering your loved ones surrounded by family.

Like · Comment · Share

12 Top Comments

Write a comment...

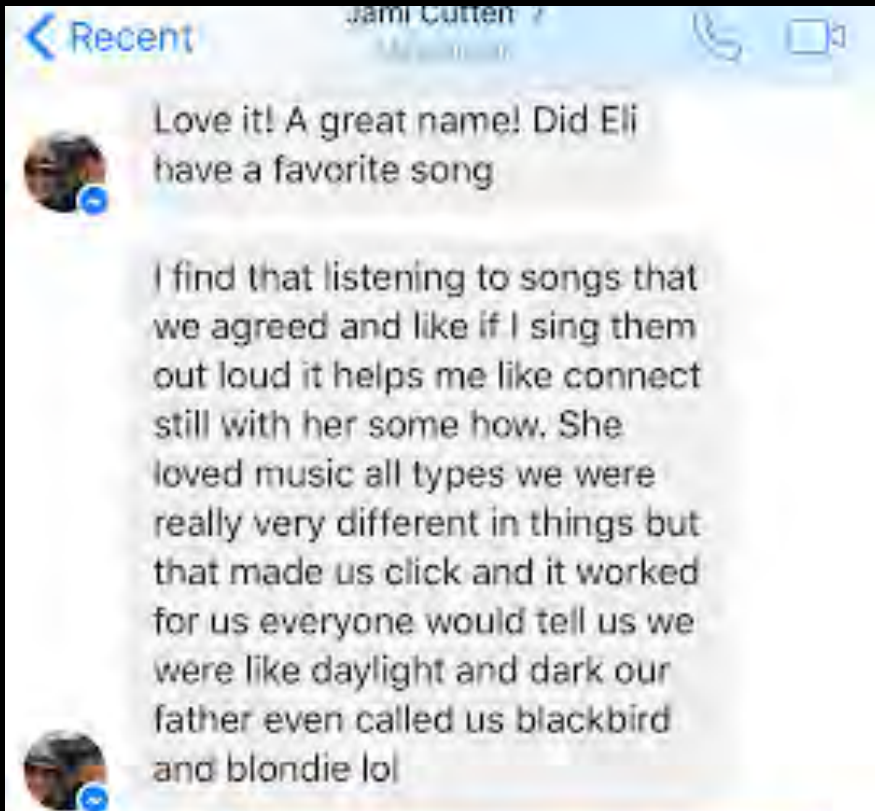
Lauren Minchen I'm so sorry. I lost my only sister in July of 2015, and it's unbelievably hard. Losing a sibling is not only losing so much of your childhood. It's also losing a big part of your future. It's a continual mourning process...But, you can get stronger to carry it. Praying peace and strength for you. I'm so sorry.
Like · Reply · 4 · March 27 at 10:34pm
2 Replies

Paulia Grzych My brother passed when he was 24 in 2004 and my sister at age 37 on 1/29/16. I'm in despair trying to live without the only two people like me gone. Today was exceptionally hard to be without them for Easter... Holidays were our favorite. And then there was one...
Like · Reply · 3 · March 27 at 11:57pm
1 Reply

View 14 more comments

Sibling Loss Support Group
February 29

From one of our group members: "I lost my baby brother at the age of 36 to suicide. If any one who lost a sibling to suicide would like to reach out to me please let me know. I also lost my older brother to a farm accident."
If you are interested in talking, please comment on this



“This is so helpful!”

Siblings can share directly on the site, but [siblingsfor.life](#) also comes to them—on Facebook. I'm using Facebook ads to extend the reach of the project, and I've also interacted with dozens of siblings in online grief groups who are voicing that they are struggling and asking for help. What I do is prompt them to share a story about their sibling, and then ask how they're sharing stories like this one everyday. I turn our conversation into a post, and then share the link to their story with them.

One participant, Alicia, told me that it really was beautiful to see the post about herself and her brother, and she could feel **how opposed it is to the way she was living her life**. She had to keep reading it to remind herself that it was true, but she got it. It was true. Her brother Brian didn't just die, he also lived. And yes, She was still his sister and their memories were real.

And yes, she was still his sister
and their memories were real.

how opposed it is to the way she was living her life

While I was expecting this tool to bring healing, I did not know what the paradigm shift would look like for each person. It seems that it ranges from existential crisis to excitement for opportunities to celebrate, since they had already been self-aware of this need.

“I would love to have known him.”

While sibling loss is a common experience, chances are most readers haven't experienced it.

I'd love to leave you with a suggestion for when you are face to face with a bereaved sibling. Rather than saying "I'm sorry for your loss" or "everything happens for a reason," you could use this opportunity to reorient how you approach this person's legacy around the **celebration of their life** rather than the emptiness of their death. You can better express your empathy more authentically with something like "I would love to have known him." It's a beautiful way to affirm that a life was lived, not just lost, and to open up the space for the sharing of a story.

celebration of life

I received valuable feedback from advisors and friends of participants who crave the ability to actually connect empathetically and with compassion in a way that doesn't feel empty or even inappropriate. While it was not my main goal, I was happy to pinpoint that others also need a script for how to create the opportunities to celebrate life together. "I wish I would have known him" is a rare way to do this. In an interview with American Greetings' director of sentiments, he told me that condolence messaging has been evolving, with a new line launching in 2015 around celebration of life. He said that this was only one direction for condolence messaging, since it is important for their lines to carry the variety necessary for a customer to choose from.

I asked the guy who's in charge of curating sentiments on bereavement cards at American Greetings how they decide what's on them. Here's how that convo went:

American Greetings does offer cards specifically for sibling loss, most notably in our Carlton Cards product line.

Sibling and "family" loss cards are written to offer mention of the familial relationship without introducing message limitations that would inhibit the purchaser's expression of care/concern/support. Balancing the message types within a selection of Sympathy cards is a critical factor to addressing multiple sending situations and relationships.

In more general terms, bereavement messaging on greeting cards is carefully edited to ensure that the selection of cards offers variety to the consumer. Card messaging can reflect a number of specific editorial attributes. Circumstances dictate final selections for the card purchaser based on their relationship with the recipient; keeping in mind with Sympathy that the card buyer may or may not have had a relationship with the deceased.

Trending messages in 2015 included a greater emphasis on celebration for the life lived by the deceased. These celebration of life messages are carefully balanced with more traditional, heartfelt, memories of the deceased, and for care and concern for the card's recipient.

A visit to any Target store would give the author further insight into the variety of message types offered for the Sympathy card occasion. Hope this helps.

An example of a positive message, from my point of view in doing participant observation, this messaging features some ideals, like celebrating the life and memory and also encouraging closeness with others:

Hi there,I'm so very sorry to hear about your loss. Wishing you much closeness with your loved ones right now. And may their memory be a blessing.

In coming days, I will be adding photos below of greeting cards I will be collecting variously. I will be giving them to bereaved siblings and recording their reactions.

siblingsfor.life

looking fwd

Next steps...

Expanding via social media

* Outreach to members of online grief groups has been a successful way to connect one-on-one with siblings in order to collect examples of opportunities. I expect to continue collecting stories at the steady rate of one a day in order to provide followers a daily example in the Facebook page, on Instagram, and on the site.

* Facebook ads have helped grow the Facebook page into the hundreds, with Americans from across the country and unexpectedly, it has gone international to every continent. Looking deeper into those trends, it appears that people who live in war zones or those areas affected by natural disaster are subscribing mostly.

Scaling internationally

* I have already leveraged Facebook ads to large and small US cities, as well as cities on every continent, especially those affected by war and natural disaster, which have unprecedented mortality rates that may not have the supports that encourage celebration of life among siblings. This would require more ethnographic research and prototyping for that audience to ensure impact there.

Partnerships

Partnerships with grief groups in New York area, Chicago to network and collect stories for the site

* Compassion Network, NYC and National

* Institute for Grief Recovery and Center for Creativity, Chicago

Looking for organizations in Middle East and African conflict zones as well as sites of natural disasters (where most of the Facebook fans are from)

Looking for partners who are developing groundbreaking psychedelic treatment of PTSD (ie MAPS) to work with sibling loss

siblingsfor.life



margarita korol

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