



Talk with Me: Communication at End of Life

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Death and Loss

The universal
human
experience....



Qualitative Study Methodology:

- ▶ Domain: Face-to-face semi-structured interviews
- ▶ Interviews transcribed verbatim producing detailed transcripts
- ▶ Iterative team line by line analysis of transcripts that determined thematic understandings



Qualitative Study Methodology

- ▶ Descriptive Narrative Study
- ▶ Purposive Sampling
(conducted 2011/2012)
- ▶ Southwestern Ontario and Westminster Maryland
- ▶ N=16 Males = 4 Females
=12
- ▶ At least 2 years post death
- ▶ Losses (Mothers, Fathers,
Spouses)



On Communication....

- ▶ I remember him saying “This is going to kill me” – it was very direct. He didn’t pull any punches and didn’t hold anything back. He was very clear. This made it possible for other people to be clear with him..there were no secrets hidden behind any curtains...It was such a blessing to have direct, right on the table communication...It clarified the whole dynamic and it deepened the relationships he had...(Participant 8)

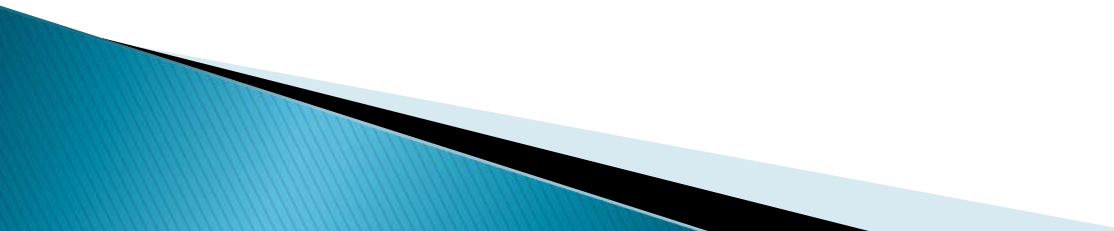
Identified Themes: Conversations

- ▶ **Conversation as Permission Giving**
 - Permission to Die
 - Permission to Keep Living
- ▶ **Conversation as Opportunity to Heal/Repair/Strengthen**
 - Loved One
 - Self
 - Other Family members
- ▶ **Conversation as Privileged Communication**
- ▶ **Conversation as Pragmatic Attention to End of Life details**
- ▶ **Conversation that enforce old conflicts**
- ▶ **Conversation through spiritual presence/dreaming**
- ▶ **Other Types of Communication**
- ▶ **No conversation about death**
- ▶ **Continuing Conversations after death**

Conversation as Permission Giving to Die

- ▶ I was telling him what he had done for me, What he had brought to my life, and that he had changed who I was...I told him all the things that he brought to my life and to my family's life. I told him what an incredible father he was and how proud I was of him for going for his dream...For him, standing before God with your sins is not a big deal but standing before God with a wasted life, then you're in trouble. You better be able to tell God what you did with the life he gave you... You know? I told him that "I'm fine -that you can go." That he needed to go. I knew he was ready..... (Participant 3)

Conversation as Permission Giving to Continue Living

- ▶ He said: “Thank you for keeping me home. Thank you for doing this so that I could stay at home.. He also said to me – I will send you someone wonderful. He said that to me. “I will send you someone wonderful..which was..which was lovely.” (Participant 3)
 - ▶ She told me to live life fully. (Participant 5)
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Conversation as Opportunity to Heal/Repair/Strengthen Loved One

- ▶ I think my father felt he let us down, and so I always made an emphasis on – “you’re not done living ‘til you’re done living.” Even though you are sitting in a hospital bed and you can’t talk you’re still teaching, you still mean something, you still matter...I always made sure he knew that, that you are still giving us what we need and so I think that had huge value to him, in his being able to understand that he did give us something valuable and that he was a good person... He just never figured out who he was. (Participant 1)

Conversation to Strengthen/Heal/Repair Self

- ▶ “So he trusted me with everything. His finances, his decisions, his belongings, his feelings. He trusted me. When he really didn’t have to, because I hadn’t talked to him for 10 years. I was the one of his children who had discarded him..I guess I was meant to be in that role because we had our work to do.” (Participant 1)

Conversation to Strengthen/Heal/Repair Self: Saying Goodbye: Not Saying Goodbye

- ▶ “In her mind there was never going to be a goodbye. She said to me a lot “Did you miss me?” a lot of that. Never goodbyes. Ever. There’ll be no goodbye. It’s just a “see you later.” “Catch you later.” She’s preparing a place for me. To us the word goodbye is a word that signifies an end to something, and we just refused to see this as an end in our journey. (Participant 6)

Conversations to Strengthen/Heal Repair Self (also permission giving)

- ▶ “ I found a way to say good-bye to him without being in the same room..It was in the backyard. We have this beautiful tree in our back yard and I just talked to him there. The essence was about forgiveness. It was around telling him that he could let go because he was in a lot of pain..... For me it meant creating closure...keeping my boundaries. I said goodbye (Participant 15)

Conversation as Opportunity to Heal/Repair/ Strengthen Other Family Members

- ▶ My son has addiction issues...I was afraid to sort of let my son struggle I wasn't sure that I was being a good mother if I would allow him to go through the consequences to his actions. My dad told me he thought I needed to give myself permission to say "no." He said "You're not a bad mother. You've done everything you can possibly do." He would remind me of all the opportunities my son has had...that I had given him food, clothing, shelter, education. Those are reasonable expectations of a good mother. My dad is the only person that could have said that to me and me accept it from him.....My over mothering was preventing him from being a complete adult.....He understood I needed to get my own life back. (Participant 10)

Conversation as Privileged Communication

- ▶ “My father was a very private person, so I knew he could not have those conversations with just anybody. So it was an honour. It was more love ...that he trusted me with that information and to have those conversations. Whereas he didn't trust my sister and my brother wasn't around. (Participant 1)

Conversation as Pragmatic Attention to End of Life Details

- ▶ Funeral arrangements, caskets, ash box
- ▶ Assign belongings and direct asset division
- ▶ Direct End of Life Care
- ▶ Research Holistic Treatments



Pragmatic Attention to Details

- ▶ He wanted us all to plan because in his mind – it made it easier not to have to make decisions so that once that person is gone you can just do what they would have wanted you to do. So he had written out things that he wanted us to say, he had written out what music he wanted at his funeral. He basically left instructions for how everything should be done, and he told us that everything would be left to our mother, that we shouldn't think we're getting an inheritance from him. If she wanted to leave us something when she dies..that's fine, but he was leaving everything to her. He wanted to make sure she was well cared for. Our stress was relieved because we had his notes and we just did what he said. (Participant 10)

Conversation that Continues to Enforce old Conflicts

- ▶ It was the last chance for her... and for him [my brother] to see her, and I wanted to make sure that she didn't want to see him and talk with him...She told me "no". She didn't want to see him and did not want him to be too actively involved in her funeral, certainly did not want him at her burial... I understood where she was coming from..Not much I could do about it except to know what her wishes were. I'm sure he's angry at me for following her wishes...so in the end it probably solidified what was already a poor relationship for many years...there isn't a relationship." (Participant 4)

Presence/Spiritual Messaging

- ▶ There are times when I feel his presence...I'm from South Carolina. People will tell you about folks who visit them and those kinds of things. My mother says that he has visited her on a number of occasions. I don't see him, but there have been times when.. I have just said "You know Daddy, I don't know what to do about this thing"...I would feel him...I don't get an answer...but I feel like OK you'll be fine...you'll figure this out. (Participant 10)



Other Types of Communication: Non-Verbal Communication

- ▶ Over time we developed little communication signals, sign language amongst two people who are deeply in love and committed to each other, and [she]and I had that. We had the ability communicate with our eyes and look into each other's soul and just speak without speaking audibly..we just knew. We'd use our eyes to communicate. She let me know where she was at with her eyes. Although her body had failed, her soul and her mind and her spirit were still strong right to the end. (Participant 6)

Other Types of Communication:

Tactile

- ▶ I probably think daily about Mom holding my hand....Her hands I remember distinctly..I loved my mom's hands, that's one thing, they are very strong hands that she did a lot with. They felt so warm. [When she was in hospital] I would hold her hand. It just felt so warm. It felt like almost the biggest piece of the communication was there...It felt very personal to me...I'm grateful that that was a way that she showed love..showed me love in the very end. (Participant 5)



No Conversation

- ▶ My mother did not want to talk about dying and denied through the two years from the time of her ovarian cancer diagnosis until the last few weeks that she was, so there was little discussion in that regard..... She just wanted to live life and didn't want to acknowledge that she was going to die. So there were very few conversations – that's my mum, that's the way she lived her life...She didn't ponder things, didn't reflect (Participant 4)



The Continuing Conversation...

- ▶ I talk to my deceased husband a lot of the time, but it is in the context of....I'll tell you the other day like..I'm doing the 3rd load of laundry after I've just done a gazillion things, and I have all these demands on me from the kids..and my conversation is usually " I am so going to kick your ass when I see you again because you went and left me with so much stuff to do"...so I have these conversations that are more about the anger piece right?...because I can't let myself have the conversations about the "miss you" piece because that is just too hard to stay together...and keep yourself together... and do all the stuff you have to do
(Participant 7)



Lessons Learned

- ▶ “ (because of the conversations) I had no regrets, I had no regrets, and am I ever thankful that I had that opportunity with my dad and I didn’t stick with not talking to him for 10 years, which would have become 11,12,13. The longer you go the easier it is. I would have been walking around today with huge wounds.” (Participant 1)

Lessons Learned

- ▶ My mother's death taught me to never really hold back what you're feeling. I have more conversations now, sometimes you put things off things you want to say – I don't keep things to myself now – like you never know what is going to happen tomorrow..... People know if they are meaningful to me. (Participant 2)
- ▶ Live life as if this is your last moment..Say to the people you love and care about the things that are in your heart (Participant 13)



Lessons Learned

- ▶ The [healthcare] system is broken. It was very frustrating for loved ones like me to have to care for our special loves and fight the system in order to protect them from the system. It was very difficult to try and keep her dignity intact..that's why I brought her home...It was one of the most difficult things I have done, but we needed to get her out of the hospital so that she could die with love and dignity and her soul intact. (Participant 6)



Lessons Learned

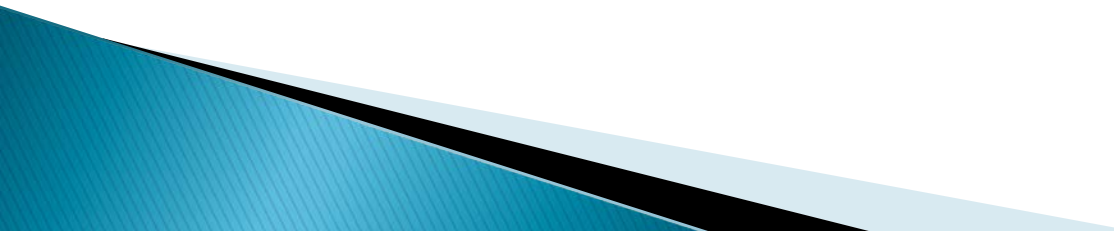
- ▶ People tend to die the way they lived...if people are “bickerers” there is some sort of version of that even at the end of life
- ▶ Often what I see...the “I love you”, the sense of connection and expression of the value of the relationship doesn’t get articulated. I used to think that people needed to say these things..but now I think it’s so...it’s a given...it so expressed in all the things that people do for one another....the caregiver’s generosity... the dying person’s apology for being a burden.....
(Participant 7)

Lessons Learned

- ▶ I can't stand the language that gets attached to cancer illness it is so much about "beating it"...or "fighting it"...or "surviving it"...There is no language in cancer right now that suggests you "don't have to beat this" - I want to give people permission to just be in it.
- ▶ In death it is not about winning or losing...It just is....right ? (Participant 14)



Other things the study taught us

- ▶ 1) Death creates changes in the Family System
 - ▶ 2) The Role of Hope
 - ▶ 3) The Internalization of the deceased....
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Changes in Family System



HOPE

▶ HOPE for the Best but Prepare for the Worst

- “Have you thought about what might happen if things don’t go as you wish? Sometimes having a plan that prepares for the worst makes it easier to focus on what you hope for most.”

▶ Reframe HOPE

- “I wish too that this disease would just stay in remission. If we can’t make that happen, what other goals might we work toward that are important to you”


▶ Focus on the Positive:

- “What sorts of things are left undone for you? Let’s talk about how we might be able to make these happen”
- (Tulsky, 2005)

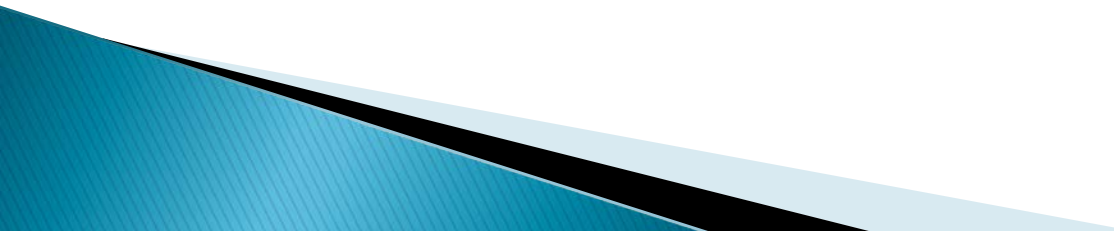
Internalization of the Deceased

- ▶ My mother came from a family where her father died quite young and was an immigrant. She was the kind of person that people wanted to move forward ..So she got to go to university, and accomplished a lot in her life...She got to go to the Olympics as a translator. She left a “You can do it...don’t let things stop you..have faith in yourself...women are smart”..All these good messages...I know the messages are part of who I am. They have become part of who I am and they carry forward in me” (Participant 16).

Role of Social Workers

- ▶ No matter how prepared people are death can induce enormous anxiety in the dying and their family members....
 - ▶ Encourage Patients and Families to Talk
 - ▶ Try and put behaviour into words
 - ▶ Be aware of the client's process
 - ▶ Be aware our own personal process
 - ▶ Be aware of professional armour so our own losses are not triggered
 - ▶ Recognize the influence of culture on conversations and beliefs
 - ▶ Do not contradict or put down other healthcare providers, yet recognize patient concerns
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Role of Social Workers

- ▶ Pay attention to affect – the feelings associated with the content of a conversation
 - ▶ Acknowledge the emotion and legitimize the feelings
 - ▶ Identify and validate the loss
 - ▶ Offer support
 - ▶ Observe/comment on systemic shifts and their manifestation in remaining family members
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THE THING IS...

to love life, to love it even
when you have no stomach for it
and everything you've held dear
crumbles like burnt paper in your
hands, your throat filled with the silt
of it.

When grief sits with you, its tropical
heat thickening the air, heavy as
water more fit for gills than lungs;
When grief weights you like your own
flesh only more of it, an obesity of
grief. You think *how can a body
withstand this?*

Then you hold life like a face between
your palms, a plain face, no charming
smile, no violet eyes, and you say, yes,
I will take you I will love you, again.

Giving Sorrow Words (2002)
Ellen Bass poet





THANK YOU