

Dancing with Death

by

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In my work at a hospice as a clinical social worker and family therapist, I have sat with people as they take their final breaths. This also involves standing alongside families members as they witness their loved one's death. This process provokes a reverence and a tremendous valuing of people's courage and resilience. Because of these opportunities, I have come to think of death and dying in ways that popular literature does not often speak about.

In this article, I wish to address the ongoing continuity of relationship. My belief is that when a person dies, a relationship does not die. When we experience death not as a finality but as an invitation to a new relationship with our dying loved one, we are breaking from a modernist approach that dictates we must "get over" our grief and "move on" in life. In spite of what we are taught about how a bereaved person should behave and grieve, "letting go" may even be a harmful pathway.

I will write about how a narrative and social constructionist perspective broadens modernist thought when incorporated into the world of death and grief. As I recount the story of one remarkable woman and her journey, I will illustrate how we can think differently about death. I will weave commentary throughout that enhances how it is that stories and connection can grow after death. My hope is that this writing will generate thought and conversation about how we can form new discourses when it comes to death and grief. I will write about how we can utilize a narrative approach to develop the relationships and loving stories in our lives during and after death.

Bill and Ellen²

Recently, I had the chance to know a family that affirmed for me how love, connection and relatedness do not have to be effaced by death. I was first introduced to this family at an inpatient hospice unit. The husband, Bill, had been transferred to hospice from the medical hospital where he had been hospitalized for the two previous days. Ellen and he had been married for forty-two years. She was sitting when I entered the room and was crying softly as she held his hand. I pulled a chair alongside her and asked if we could chat. I knew from a brief review of his medical records that Bill had been in a coma and unresponsive since being brought to the emergency room by the helicopter transport. And I knew that his physical condition was the result of a massive stroke. What I did not know was any of their stories that would bring this dying man to life for me.

Bill and Ellen had been on vacation the previous week when Bill had had this stroke. Prior to this, Bill's health had always been good. Ellen tearfully told me how they had looked forward to this vacation as a statement that they were ready to resume their 'normal lives'. She told of how they were in the process of reclaiming their marriage and lives following the difficult events of the past year. 'You see', Ellen said, 'both our children died last year'. I could feel the potential enormity of her situation as she shared this with me in the presence of her dying husband. I could not begin to imagine the pain

she had had to endure and felt my body tense from just the thought of it. She elaborated, 'Our daughter died from cancer last fall. She had been sick for a couple of years'. Ellen told me their daughter was thirty-eight. 'Our son died three months later from a heart attack.' She explained that his death was unexpected and that he was forty years old when it happened.

As Ellen placed her family's events in context, I was shaken by how much she had already shouldered. And now, she was facing the loss of her husband. I knew that from his physical symptoms, Bill's death would be imminent. Three such deaths in the space of a year seemed to me to amount to more than what a person should have to bear. I was concerned about Ellen; concerned about what this would mean to her.

Joining and assessing

There were several things uppermost in my thinking at this time. I was interested in forming a connection with Ellen, joining with her sense of what might be helpful at this time. This required me to take a stance of learning about how I could support her rather than assuming that I knew what might be helpful. In order for this process to be respectful and collaborative (Anderson 1997), it was necessary for the pacing to be established by what she felt comfortable with; that is, for Ellen to establish the level of involvement I was to have with the intimate details of their lives. I was gently curious to hear more, but I wanted to defer to her to guide and direct our conversation. I was especially cognizant of this as we were in a medical setting where Bill's body may have already been poked and prodded. I did not want to add to possible intrusions by insisting that she speak about things she was not ready to.

As I sat with her, I was thinking of Ellen's potential risk factors in what lay ahead. I could feel my concern for her growing. I thought about how someone faces life with the three people closest to her all dead within a year, without perhaps wanting to die herself or, at the very least, become overwhelmingly despondent. In my thoughts, I was wondering what Ellen knew about her own story of courage and resiliency. How does she think of herself as responding to extreme challenges? I was curious too, to know more about her community and spiritual resources. How has she utilized these things in other times and might they be of assistance in what lies ahead for her life.

In my initial assessment, I also wanted to know about her understanding of what was going on. To this end I asked her questions about her knowledge of the situation. I hoped this would give me a great deal of information about how she was forming this knowledge and where I might have been able to best support her. This included asking about what sense she was making of the medical information she was receiving. How has his condition been explained to her? What does she think that the next day will bring? These inquiries let me know if Ellen believed her husband would live or die. As Bill had been transferred to the Hospice unit, I could assume that his physician believed his death was imminent, but this explanation may or may not have been shared by Ellen.

I also started to make gentle inquiries about the numerous options she had yet to decide. In recent modernist culture, the handling of death has often been removed from families and left to the undertaker. Many people have never even seen a dead person let alone prepared a body for burial. What to do with a corpse now comes with a myriad of choices, each potentially overwhelming in itself (Quigley 1996). I wanted to discuss with

Ellen some of the things that she would soon have to face, such as cremation or burial options, but was aware that many people shy away from these details. My hope, in opening space to discuss this was not to appear blunt, but to provide a platform for her that would be congruent with their preferences. Handling details like organ donation and funeral arrangements could increase agency for her at a time when other things appeared beyond her control. I tentatively broached these topics by asking her about how they handled the details of her children's deaths. Were they buried or cremated? Had they thought about these details as well for themselves? Would they want it to be similar or different? It is not uncommon when I speak about these things that people wish to reflect about their choices over time whenever possible. Even though we probably only had a short while, I elected to ask Ellen about other things as well as she thought through some details.

Inviting stories about Bill

I wanted to get a sense of her life with her husband and in the process seek out the smallest stories of hope and sustenance in an overwhelmingly grim situation. I invited Ellen to reflect about her husband. What things about him did she come to value the most during their marriage? How would his friends have described him?, I asked. What would they say they admired about him? I also inquired about this man through the eyes of his deceased children and asked her to share with me stories about how they too were touched by his life. She told me how he was a proud father who loved walking his daughter down the aisle when she got married and how he adored his three grandchildren. But most of all, Ellen valued the laughter. She described Bill as 'a real live-wire' and very involved with the Polish community in town. He was known as a storyteller and entertained with jokes and tales. He was a physically large man who loved to dance and sing and eat. Particularly he loved to polka. I sat with her for some time as she reflected about his life through many perspectives, both her own and others. Ellen painted a picture for me of a wonderful man who was full of life and love.

As the day went on, some of their friends came to be with them. They added to the richness of the stories that Ellen had been telling me. Periodically, I would step into the room in between my other social work duties on the unit and hear snippets of details from his friends that reflected how loved this man was. They laughed telling the sweet remembrances of Bill's life; of his love for sausage and beer and mostly his love for polka dancing. I was beginning to form a meaningful understanding of Bill even though he and I never exchanged a single word.

Standing up to the dominant discourse about grief

In this context - at the bedside of a dying man - time was very precious. I was cognizant of this as I shaped the questions that I asked Ellen. She did not have several months to prepare herself for her husband's death. Nor did she have the luxury of being able to spend time completing 'unfinished business' with him or adjusting to a life without his physical presence near by. She could not conveniently progress through any

pre-planned steps to assist this end. This was the stark reality of life and death. I wanted to help Ellen access any practical stories of hope very quickly. I chose to ask questions that were inviting her to celebrate her husband's life, rather than only to focus on his death. I did not ask her if there were things she needed to say to her husband before he died. I did not assume that if she did not utter final words of some critical import that she would be doomed to unsuccessfully grieve her husband's death. Rather, I made a conscious choice not to join with the dominant discourse in this situation which could be voiced in words like, 'Oh how horrible! This will take you a long time to get over. You will need lots of bereavement counseling or support groups.' Instead I assumed that there might exist an alternative story to the tragic one, even though this alternative story might still be small and not yet very loud. Even in the midst of what appears to be tragic, I assume that something good can be born. There are still many possibilities for laughter and love in the presence of death and pain.

I also was interested in knowing Bill through her eyes as well as the eyes of others. In asking Ellen questions about how others found him, I wanted to bring forward and thicken her knowledge of her husband by placing his life in context of their family and their community. Our communities, in all their shapes and forms, serve as healing audiences in times of duress (Myerhoff 1980; White 1997). My questions were in the hope of reminding Ellen of the communities that she and Bill had established and anchoring her in some way to them so that their resources would be accessible to her during this time and in the future.

Some of my questions were specifically geared towards creating space for Ellen to more richly incorporate Bill's presence in her life and identity (White 1989, 1995, 1997). Through this process, I hoped that after Bill's death, Ellen would be more likely to be able to remain in relationship with her husband and that his voice may remain available to her to offer guidance and comfort. I wanted the communities Ellen was involved in to play an active part in this. I hoped that they could provide now and in the future a virtual or tangible audience for the ongoing production of Ellen's relationship with Bill.

Keeping Bill's voice alive

I asked her questions about how he was when their children had died. I wanted to get a sense of how they supported one another through these difficulties and how she knew her own resiliency. Ellen told me during these understandably terrible times how she found comfort in her husband's words and embraces. I wondered what she imagined her husband would say about how she would cope with this. 'If he were able to speak', I asked, 'what would he say that he was proud of you for now? What would he notice that you were doing well? How would Bill expect that the strength of your forty-two year marriage had contributed to you being prepared for this?'

I asked questions too about what he would have to say about their relationship as well. 'Who would he say that they were as a couple?' In response Ellen talked about her husband's belief in her and in their marriage. She said that he had always described her as 'feisty' and speculated that we would see her pulling through this as well. She spoke about how much fun they had had together. Again, Ellen mentioned his love of polka music. He loved its upbeat tone and spirited mood. Remembering this fitted nicely with her picture of Bill's approach to life.

In the dominant discourse about death and grief, this should have been a time of saying goodbye. My purpose was different. I wanted to know the impact that this man's life had had on her, on their children and on others. I was also intentionally inviting her to participate in a process of reflection on this impact. I wanted to magnify this impact, make it larger than life, even to immortalize him in her eyes. It would mean asking questions to bring vitality to the details and enrich the text of these wonderful accounts (White 1995, 1997; Freedman & Combs 1996). This involved bringing images and stories of his life into sharper focus and adding to their complexity rather than treating them as if they were fading away with his consciousness.

I believe people do not want to be forgotten. Nor do those who care about someone who is dying or has died want to forget their loved one. The dominant discourse of grieving encourages forgetting, getting over grief, moving on (Vickio 1999). I believe this is a disservice to the rich stories that we all carry. By asking generative questions of Ellen about what she imagined Bill's lived experience has been, I am inviting her to join me in the re-membering of Bill (Myerhoff 1980; White 1995, 1997). This process looks towards the continuation of Bill's presence in Ellen's life as an important and vital relationship.

Rather than walking into this woman's life and acting on the assumption that she needed to say her final goodbyes to her husband, I assumed that their relationship was going to continue, albeit in a different form, even after he was dead. I was inviting her to step into new forms of this relationship in which she might need to work harder at keeping his voice alive in her own mind. His 'internalized other' voice (Tomm 1987a, 1987b, 1988, 1995) would have to be more active in future conversations as she would not have his alive voice there to reinforce these conversations. I wanted Bill's presence to be available for her even as she negotiated the terribly challenging time of his death. My questions were intentionally geared to encourage his confidence in her to be revitalized again and again. I imagined that she would need to draw on this in the coming months. She would actually have to become more skilled at calling up his voice in a powerful way from this point forward.

I assumed that Ellen already had a lot of knowledge especially from her recent experience to draw upon in handling adversity. Some of these strengths may have grown out of the extreme hardship she and her husband had faced in their children's deaths. Ellen may or may not have had time and opportunity yet to describe these as strengths and my questions were designed to assist in bringing this story forward; that is, to invite reflections about how well she had been managing through it all.

This form of thinking and questioning is set apart from the dominant discourse about grief. The prevailing constructions would have potentially labeled Ellen as suffering from some form of grief reaction. I wasn't interested in pursuing this type of conversation. These models, based in deficit ideas, only inhibit our coping abilities and undermine our confidence (Gergen 1994; Winslade & Monk 1999). Rather, my inquiry was both pragmatic and intended to access her unwritten stories about her own courage and strength. This form of conversation calls forth from people their ability to rise to the occasion, to handle things they did not know they could. Life will go on for Ellen in some fashion. My concern, even in my brief contact with her, was about the caliber of experience that she would draw from as she went forward in life with these circumstances. How could I increase the likelihood that Bill's dying process would include positive things she could reflect upon and utilize to reinvent her relationship with

her husband? My questions were about asking her to step into an ethical position of caring for her own resourcefulness through enhancing her story of herself as a person of caliber, courage and resiliency.

Last rites

That afternoon, one of their friends had brought to the hospital a walkman cassette player and polka music. Ellen had mentioned that someone in a coma could still hear even when they are not conscious. The walkman was placed over Bill's ears, and the oompa oompa beat of the polka could be heard by others in the room. His friends were enjoying telling stories of how fitting this was when the priest arrived to administer a sacrament to the sick. Being Catholic, Ellen had requested that the priest visit. True to Bill's life, the polka music kept playing while the priest administered the blessing and bedside prayers were said.

I was away from Bill and Ellen for a while but when I returned at the end of my day, I found him still with the headphones on listening to the polka music. Even though there was no visible response from him, it seemed to be giving her a great sense of comfort. Ellen told me how she imagined her husband was laughing irreverently at the image of the priest administering the sacrament to a man listening to polka music blasting out from under a walkman. He too would have loved the irony, she said.

I asked her if she imagined he was dancing. Her eyes lit up with her reply. 'He is dancing his way to God', she said. I asked if he would like that as a way to die. Ellen thought he would. We talked for a few more minutes about the idea of Bill's dancing his way to God as only appropriate for his life - a sort of 'dying with your boots on' kind of metaphor. She and I hugged as I left for the day and I thanked her for the chance to know Bill through her loving eyes.

A resounding metaphor

This moment was not predictable. Had I been looking for a particular stage of grief, I may have missed the richness right before us. Together we had co-constructed a metaphor that had a resounding connection with his life. As we talked about it, a story developed around the metaphor. This was not a story inspired by a universal account of the stages of grief that Ellen should be going through. Neither was it a tragedy. We had created a positive story that I hoped had enough impact to help shape her experience of her husband's death. It was a story that included lightness and humor rather than just heaviness and sorrow.

Her gentle smile indicated to me that she found this story helpful at this time. I hoped that this would continue to be potentially a healing and comforting story for her. I imagined her telling people at the funeral and afterwards about how he had died, dancing his way to God, I thought of her telling this story over the years to come to their grandchildren when they reminisced about Bill's life. It was a story of great hope and positive legacy that grew from a small moment. It was also a story of courage and love that Ellen would have available to her for the rest of her days.

This story encapsulates to some degree my work with families in a hospice setting,

where I have found a narrative approach to be highly beneficial. My emphasis in this work is upon the following principles:

Affirming the ongoingness of life and relationships rather than dwelling on the finality of death.

Appreciating how the emergency of death provides opportunities for the telling and performing of loving stories that I hope will linger long after the death.

Asking questions to generate affirming and resourceful memories of this time for future times of reflection and re-membering.

Using questions to bring forth creative thinking within the constraints of otherwise fixed realities, such as time and proximity.

Seeking out with people the resources they can call on for handling the challenges of transition that death brings.

Employing the power and flexibility of story to transcend physical mortality.

Promoting the re-membering of lives and relationships.

Refusing the assumptions that people should complete a process of farewell and letting go in order to progress healthily through the crisis of death.

These principles amount to a distinctive way to think of death and grieving. I believe it is a respectful approach. It requires me to graciously join with people in challenging times and work with them to co-construct stories of hope and love.

I left that evening with hope; hope that these brief moments would make a difference over time in Ellen's life. In total, I was only involved with Ellen's and Bill's life for about four hours over the course of one day. I learned later that Bill died about two hours after I left. He was sixty-seven when he danced his way to God.

Dedication

This paper is written in remembrance of Fred den Broeder. On the same day I learned this story was in press, Fred died. In his fight against cancer, he reminded me about courage, bravery and persistence and the fragility of our bodies. So my friend, let's all remember 'there's always one more good hoorah'.

Notes

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In order to respect privacy, names and potentially identifying information has been changed.

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