

For close to four years, Jennifer de Jong (JJ) and Linda Clarke (LC) worked on a project that focused on the stories of “good death,” which patients, caregivers, palliative care nurses and physicians carry with them into the palliative care context. At the time, JJ was a medical student; she is now a family physician in her third year of practice. LC is a writer and a storyteller who works as an artist and educator in health care and medicine. At the beginning of this project, she was the facilitator of the narrative medicine program at Dalhousie Medical School in Halifax, NS, Canada.

LC: This project generated a lot of reflection for both Jenn and me. When she was a family medicine resident, we decided to be more structured about our dialog. We formulated a set of questions to guide our ongoing discussion of the value of such story work, using our experiences with the palliative care project as the context of our reflections. This dialogue continues. With time, of course, things have changed. Jenn has had more years of practice to frame her considerations, and I continue to have experiences with story which shape the way I see things.

One of the characteristics of story work in health care and medicine, including in research, is that it can be “counter cultural.” That is to say, it is framed differently, experienced differently, than the clinical discourse that is more “mainstream” in health care and medicine. In keeping with this, we present our reflection in this style of conversation. As with the project that we discuss, the learning happens with the story and the dialogue about it. Our intention is to outline the value of story work for the learner and the mentor. Much of our learning happened in our ongoing dialogue.

We feel that our reflection process provides a useful context for further work in narrative for both of us and may be of interest to others who are using “narrative health care” in one of its many iterations. Below are some of the key points of our dialogue thus far.

LC: It was bitterly cold that January evening I was meeting with a new group of medical students. The opening invitation was, “Tell the story of when you decided to come to medical school.” Jenn’s story was the one from palliative care.

From that meeting, through her four years of medical school, Jenn and I worked together on a number of projects involving story. The major focus of our work was a research project on stories of good and bad deaths. Through Cancer Care Nova Scotia, Jenn received funding for two phases of “What is a Good Death?: Stories of Palliative Care.” It was my privilege to be her supervisor in this work.

The first phase of the project began in the summer between Jenn’s first and second years of medical school. The participants in the project for that phase were patients in the Palliative Care Unit of Capital Health in Halifax, Nova Scotia, their caregivers, and palliative care physicians. The second phase of the project took place the following summer with interviews of palliative care nurses. Jenn conducted all interviews one-on-one in the setting of the participants’ choice. The transcription and analysis of the interviews were completed during the second and third of year of medical school. For two years following the collection of the material and the analysis, Jenn made numerous and varied presentations about the project. She is the lead author of an article presenting the study and our findings. ¹

1. Why were you interested in doing this narrative work?

JJ: As an undergraduate student, I had volunteered in the palliative care unit of the local hospital. It was a pivotal time. I had not yet been taught the “hidden curriculum” of compartmentalization between the medical practitioner and the patient. I did not have the framework or knowledge of disease, illness and symptom management to help me understand in medical terms, or with medical eyes, those who were patients. Instead, my framework centered on people (rather than “patients”) and their families, and their coping with living with dying. During my first year of medical school, I became very interested in death and dying, and was also interested in how my perspective on palliative care may have changed, given the new medical framework that I had been taught during my medical school training.

In my medical school we saw patients early in the first year, and I felt that I did not have the knowledge to help them in any substantial way. I would listen to their stories and feel very inadequate about how to approach a diagnosis or physical exam. At the same time, I was having marvelous new experiences and began to understand how the layers of human nature and relationships impact not only the health of the individual and their medical experience, but also strongly influence health outcomes. For the first few months I was overwhelmed, unsure of how to approach these new and gratifying, yet stressful, experiences. I overcame my shyness one January night, and attended Linda’s medical humanities workshop on story and storytelling in medicine. There, I was delighted to find an avenue to integrate my new, fresh experiences into my own story and to learn to tell my new story in a meaningful way.

As summer approached, Linda and I brainstormed a research project that incorporated narrative and palliative care. The chance to explore ways of bringing these interests together in the context of a research project was exciting.

LC: I was quickly impressed with Jenn's openness to explore the many uses of story in the context of the privileged practice of medicine. Story work is often intimate, and some students are chary of it. At the medical school, we worked with the students' personal stories as a way to appreciate the importance of one's story in one's life, relationships, and community. As this work progressed, the students gained a deeper understanding of the roles of story in their own lives and in the lives of those who would be their patients. Some are more attuned to this learning than others. For Jenn, it was a good fit. Her research project provided a rare opportunity for a medical student: dedicated time and resources to further the understanding of story in the lives of those who are experiencing the deep events of their lives.

2. What was it specific to palliative care that made this project attractive to you?

JJ: There is a certain rawness in palliative care. Regardless of where people are in their disease course, how long they have had to deal with their prognosis, and whether they have the means to cope with their situation, people who are living with dying are in a state that is new to them and their families. They are coping in the best, and, oftentimes, the only way they know. Emotions are highly charged; grief is palpable; change is inevitable; and almost everyone involved is vulnerable. There is hope and despair, joy and sorrow, pain and comfort. Virtually everyone will go through these types of experiences, either themselves or with a loved one. There is much to be learned from those who are dying and those who are caring for them—what do those living with dying want? Are we providing the support needed? What constitutes a good death? A bad death? Are the perceptions of good and bad deaths the same for everyone or vastly different? These were the questions that were asked of patients, their caregivers, palliative care physicians, and nurses in the interviews. The participants were asked not only to tell the story of

a good and bad death that they had witnessed, but also what the story of a good and bad death would be for themselves personally.

LC: There are numerous characteristics of palliative care that make it a good setting for story work with patients, and with those who attend them. These include the focus of the care; the understanding that, for those who are dying, the need and desire to tell their stories can be strong and is, potentially, a healing opportunity; and the recognition that those who attend the person who is dying also need care. In addition, the palliative care program in which Jenn conducted her research is one in which there has been a strong interest in, and support of, the humanities in health care. A supportive context is important for the development of young physicians and it was my hope that the health care professionals in this palliative care program would be nurturing of Jenn in this intimate and challenging work.

3. Before you began the work, what ideas about the roles of story in health care and palliative care did you have?

JJ: The use of story for me, personally, has been therapeutic. It has allowed me to explore the parts of events I have experienced that were most meaningful and were most painful. Story can provide integration into the person rather than a descent into chaos. Given this, before I began the work, I thought that story would be a very useful way of collecting and understanding experiences that people had about death and dying. I also thought that the use of story in research would give a unique perspective on palliative care that would not be elucidated by questionnaires. While I knew for myself that story is therapeutic, I did not anticipate how therapeutic it would be for the participants to tell their story.

4. What were you most interested in through this project?

LC: I am always interested in seeing how the stories one carries into the deep events of one's life impact the way those events are experienced. As an artist-educator in health care and medical education, I was very excited to witness the dialogues that Jenn facilitated with the participants in the project. In medical education, there are all-too-few opportunities to enter into such personal encounters as the ones that Jenn was able to do through this work. Patients, caregivers, nurses and doctors were included in the project. I was very interested to see how Jenn's encounters with people in each of these roles would differ. In the culture of health care, certain voices are often considered more credible, or, more "hearable," than others. Jenn's work provided a window into these cultural differences. For example, her position as a young, female, medical student impacted the character of her encounters in this project. It was a clear reflection of the fact that where one is positioned when telling or hearing a story shapes that experience in very particular ways, for both the person who is telling and the person who is hearing the story.

5. When you reflect on the experience of this project, what did you learn about the roles of story in health care?

JJ: I learned about the paramount importance of listening to the patient's story, not only for learning but also for the patient's own healing. I also learned that to sit at a bedside, or with a family member, even for a few minutes, can provide comfort. I learned that the types of story told--grief, anger, despair, hope, memory--all serve a purpose for the person telling the story. The listener not only learns more intimate details about the teller, but also is able to share in the teller's experience. I also think story is an incredibly underutilized therapeutic modality.

LC: Jenn's work seemed to have considerable value for the patients and the caregivers who were interviewed, as reflected in the detailed stories and the amount of time that each of

these participants devoted to the interviews. The time given by the caregivers is particularly notable (three hours in one case, for example).

Jenn's encounters with the patients and the caregivers were, in some ways, smoother than the encounters with the nurses and the doctors. There are a number of reasons for this difference, and I would posit that, in part, it has something to do with the nature of the professions of nursing and medicine: the disclosure of personal information, even in the context of this study, is usually considered inappropriate in the professional setting.

Jenn's work demonstrated for me that story work of this kind is an invaluable tool for the health care practitioner to forge a relationship of a particular kind with the person whose story she welcomes. While there are limited opportunities for this kind of encounter in the usual medical practice, for certain practitioners, story work may contribute to the development of a sensitivity to, and awareness of, the importance of the personal voice. The impact of welcoming the story, or of blocking it, can be profound. For the learning practitioner, this is an important insight.

This kind of story work requires considerable sensitivity and compassion. It is important to recognize that such skills can be nurtured, taught, mentored and modeled in practitioners and that this development is especially valuable in certain sectors of the health care community, palliative care being one of them. This learning requires guarded time and space to best be accomplished. Projects such as this create the opportunities for nurturing these skills, which will then be valuable in other clinical settings.

In addition, I witnessed the way these encounters and the receiving of the stories impacted Jenn. In so many ways, it was an affirming experience for her. As with many medical

students, the shift into the clinical role and discourse was worrying for her. She was concerned she would not be able to be involved subjectively with her patients and that she would lose some of the person she knows herself to be. Facilitating these encounters, welcoming these stories and acting as a repository for them was nurturing and strengthening for Jenn. It widened her gaze.

6. The relationship of researcher/learner and mentor was key to this project. Can you discuss this?

LC: The nature of story work of this kind necessitates a close relationship between the mentor (LC) and the learner (JJ). It is work of an intimate nature, and, unlike the clinical procedures Jenn was learning in her medical school training, there is no sharply defined clinical process or objective methodology for it. Additionally, receiving such stories required an openness on Jenn's part. Throughout, she needed to be supported and to have the chance to debrief, to be moved, to fret and to celebrate. She needed to tell her stories of this work. Receiving those stories and supporting Jenn were key roles that I played as mentor.

Even as a student, Jenn was a gifted clinician and researcher. She knew the theory of narrative well; her experience working with story that winter term and completion of an exhaustive annotated literature review were strong foundations. Still, she worried about what she would have to offer the participants in the study. Open-ended interviews are not often taught in medical school, and the deliberate valuing of the subjective and personal was something that does not always comfortably fit the medical discourse. In the early days of the interviews, Jenn wondered what the right thing "to do" would be in the face of the stories and encounters she was going to be facilitating. She soon learned (as I knew she would) that the encounter, the invitation to tell one's story, is often the thing "to do." To be the repository for such stories is a privileged

role indeed. It requires considerable strength and compassion and support. Support is what I could offer Jenn as the project progressed.

In spite of the increased, and increasing, understanding of the importance of the personal story in the medical community, it is still often questioned, and, in some cases, doubted. As a faculty member and her supervisor, I worked to be sure that Jenn's work was seen as valid and valuable, even if it didn't fit the more mainstream clinical paradigms. My many years of working as a storyteller in health care and medical education equipped me to understand her experiences and gave me the voice to be able to advocate for her and her work. My experiences have also shown me the difficulties of bringing this work into the more mainstream context of medicine and medical education. I could commiserate with her on the challenges she sometimes faced.

Stories invited and stories told do not have sharp boundaries around them. They are not static by nature. Over and over again Jenn entered into these relationships with patients, caregivers and health care professionals, and each time, she was changed by the encounter. As a storyteller, I know that we are written upon by one another. To witness this and to help facilitate it was a changing experience for me as well.

JJ: The mentor/learner relationship is intimate and complex and requires trust and open dialog. At the commencement of this project, I had no idea how invaluable this relationship would be, and I am certain that the success of the project is directly related to the mentor partnership Linda and I have. The receiving of such detailed and emotion laden stories was a privilege for me, but also required tremendous energy and was emotionally exhausting. With Linda, I was able to debrief, to discuss the day's interview, to cry about a story told and to vent

when needed. Each interview provided a window into the experience of the participant and allowed me to have a deeper relationship with each one. Linda taught me how to retrieve stories during the interviews, how to receive them, and then how to re-tell the stories in order for others to learn. Further, the mentorship allowed me to learn empathy in a way that I may not have learned empathy otherwise. In my professional life, having a mentor (who continues to be a mentor) allows me to have deeper relationships with patients than in the traditional medical world. I am reminded to learn and listen to their stories, and in so doing, to see the whole person, not just their medical issues.

7. Is there specific value of story work in the medical encounter? In medical education?

JJ: Story has great potential in the medical encounter. In the early stages, as a learner in medicine, mastery of the skills of communication was a key learning objective. The communication skills were practiced under the guise of the medical interview, a highly structured template for elucidating key information from patients in order to narrow a diagnosis and start the formation of a plan. The learner physician follows the strict guidance of the interview. For fear of missing a vital piece of information, students go through the paces of the interview by rote memory and often fail to listen to what the patient actually states in response. While communication skills were seemingly taught, the actual listening to the experience, the story of the patient, and, thus, the relationship between the patient and physician have many opportunities to be inadvertently overlooked, simply missed or blatantly ignored. Story work can be a counterbalance to this more structured approach.

Interestingly, although many medical students go into medicine to “help people,” sometimes it is the very people they seek to heal who are ignored. We speak about the interesting

“case,” not Mrs. D with lung cancer and metastases. We speak in jargon, acronyms and medication names that patients and their families often have trouble understanding. While the medical humanities are gaining ground in some medical schools, the implementation of medical humanities, and, in particular, reflection, is not a part of the core curriculum of many medical schools. In my experience, there was no forum in which to reflect on a particularly horrific trauma or difficult or complex patients or encounters, no place to grieve for a beloved patient who died, or to air concerns about a potential mistake, however minor. Debriefing was often done informally amongst friends. Story allows a type of debriefing to occur. It allows us to make sense of our experiences and provides a space for openness.

LC: This kind of story work provides an opportunity for a personal encounter through which one may see new things, may develop new insight; it is a chance to recognize the role and importance of the personal and the subjective in the clinical encounter and in the caregiving relationship.

8. Why do you think your subjects wanted to take part in the project?

JJ: Participants welcomed the opportunity to further our understanding and educate others about death and dying. Through their incredible generosity, we were able to understand more comprehensively the components of good and bad deaths, both unique to the participant and universal. Some participants wanted to share their stories about dying and death simply because they were invited to and were offered the opportunity for conversation. Conversation led to connection. Others sought out the experience for a more therapeutic benefit. Professional caregivers welcomed the opportunity to tell some of their most haunting stories. One nurse stated: “To try to understand, myself, what happened and to make sure it doesn’t happen to

someone else.” It was also evident that the professional caregivers were incredibly compassionate and committed to providing the best care to their patients and dedicated to furthering our understanding of good and bad deaths.

9. Can you comment on the experiences of the different participants? What does this work tell you about the culture of health care?

JJ: All participants spoke passionately about a life well-lived as leading to a good death. This instilled in me the importance of living in the present, of living fully and of having strong relationships with loved ones. To learn the importance of living well and of loving well is paramount to a good death, and is the center of a good life.

The care providers’ stories were very moving. They were intensely emotional and involved, and the length of their interviews was double that of other participants. This spoke of the need to allow caregivers to tell their stories in a welcoming environment.

Nurses’ stories of bad deaths spoke of regret. They felt that they had failed the dying patient by not meeting his/her needs or by not being able to maintain symptom control. They also spoke of miscommunication or inadequate communication among team members in their bad death stories.

LC: It is important to note that these are particular patients, nurses, physicians and caregivers whose observations are specific to their own interactions with Jenn. That said, these observations provide an opportunity to consider the experiences of the wider palliative care community.

Patients: The stories of those who are living their dying are more halting, more raw, less smooth than the stories of those who are attending them. Those who are dying are spare in their words. There is often a poetry to the images. For those who are dying, their stories are

often their bodies as well as their words.

Caregivers: The caregivers were full of stories, hours of them. They seemed to be longing for connection and the chance to speak of it to someone else. The invitation provided them with the chance to be known, and, in some fashion, to ease the suffering that the experience of isolation can bring.

Professional healthcare providers: The interviews with nurses and doctors elicited stories of a different character and tone than those of the patients and their caregivers. There are, of course, many reasons for this. In part, I would posit that the different professional role of the nurses and the doctors shaped the intimacy of the encounter with Jenn. We are not often comfortable, in the community of health care and medicine, with sharing personal stories. Additionally, as a young, female medical student, Jenn's relationships with nurses and with physicians would be shaped in such a way as to make disclosure less smooth. As stated above, where one is standing when one experiences, speaks, or hears something, impacts what is experienced, spoken, or heard.

10. Tell about the highlights of the project for you. Why are they significant?

JJ: The project offered many poignant moments. The participants graciously allowed me to hear their stories, to enter a part of their lives and their experiences. This offered tremendous learning opportunities and insights. I became comfortable talking about death and dying, and perhaps even more important, comfortable talking about bad deaths, which were often laden with emotion.

Through the course of hearing the stories of good deaths, it was clear to me that many participants felt that a good death was one in which those who were dying were not alone.

However, in asking these particular palliative care patients to tell the story of a good death for themselves personally, they wished to die alone and not be bothersome to their families. I was surprised at this, but then realized that, out of their love for their families, patients did not want their loved ones to suffer. The generosity of thinking of others does not stop when someone is near death. I was able to hear the stories of fear of death, loneliness, troubled relationships and grief. At the same time, I heard stories of joyful times, moments of content and beauty. It awakened the opportunity to see death from the perspective of the spiritual rather than medical viewpoint.

Through this project, as a medical student, I was able to hear the stories of future colleagues. In listening to the nurses' stories I gained insight into the frustration and feelings of helplessness that sometimes occur when the nurse is at the bedside trying to convey a patient's distress over the telephone to the on-call physician. Listening to the stories of the caregivers, it became clear that they were suffering and grieving and valued having the opportunity to tell their stories. The value of story in healing and grief was striking. Perhaps most important, the project has allowed me to carry the words and experiences of others throughout my medical education and into practice.

11. What are the most important insights that you gained from this project? How do these insights impact your current practice?

JJ: Going into the narrative medicine group on that cold January night, I knew that I would enter a place of enjoyment in telling and receiving stories. What I didn't imagine is that it would lead to a project that allowed me to invite and listen to the stories of death and dying for

those who were intimately involved in palliative care. The experience has profoundly influenced my approach and relationships with patients.

LC: Over and over again, I have worked to educate about the value of welcoming and receiving the personal story in health care and medicine. Evaluation of its success is less concrete than evidence-based practice and the empirical data that is favored in medicine and medical education. Much of the evaluation, for me, has been reliant on informed intuition. Over more than 20 years, I have witnessed the way that story has helped to generate insight, has evoked empathy, has built relationship and community in the context of health care and medicine. It has been more rare to observe whether and how these things evolve and affect the individual as she moves beyond her formal education into practice. Intuitively, I know there would be a positive impact but I am also aware of the very real constraints of the “real” world. Jenn’s work on the project, and our ongoing dialog, have been affirming for me as an artist and educator. From this point, on, I can use this experience as a marker of the effectiveness of story work for those learning to be doctors. I am grateful to Jenn for what she has taught me.

JJ: I have carried lessons from the project with me throughout my medical education and beyond into practice. I have spent time with family members, talking about their loved ones’ illnesses and care plans. I have pulled chairs to the bedside to discuss the day’s events with patients. I have used story as a tool when the traditional medical questioning becomes ineffective. I have witnessed the therapeutic benefit of story for patients and their families. I have learned that when a practitioner invites and hears the story of his/her patient, it builds a therapeutic alliance, enhances the patient doctor relationship and builds community.

LC: I am confident that Jenn is a better doctor for having had these many opportunities for the intimate connection with these people. Through her, I have again learned that these

difficult conversations can be had in a way that is constructive and affirming. I learned that these are skills that serve medical students well and that they are key to the development of a practitioner who understands the value of the individual who is the patient and has begun to understand the nature of the community around her. And I have learned, again and again, the role that the culture of health care and medicine play in the way stories are told, received, and valued.

For years I have understood that we want to be known to one another, and that there is suffering when we are not known. At the heart of good care is the welcoming of the other and the acceptance of the person and the stories that have shaped them. The connection that is wrought through attending to one another's stories can be profound.

References

- De Jong, J. & Clarke, L. (2009). What is a good death? Stories from Palliative Care. *Journal of Palliative Care*. 25(1), 61-67.