

# From suffering to transcendence

## *Narratives in palliative care*

Maria Auxiliadora Craice De Benedetto MD Ariane Gianfelice de Castro MD  
Elsi de Carvalho MD Rokia Sanogo MD Pablo González Blasco MD PhD

Working as family physicians in an academic palliative care ambulatory clinic in Brazil has taught us many lessons. We have learned, for example, that even if a story's only possible ending is death, it can be written in many ways. The various people involved in a story—patients, patients' families, family doctors, and family medicine residents beginning their traineeship—experience it according to their own perspectives and interpretations. Any situation can have unexpected meanings for each of us. The most important lesson we have learned is that, even if the end of the palliative care story is inevitable, its course can be changed. The direction of the changes often depends on the nature of the patient-doctor and the family-doctor relationships.

The first encounters with terminal disease are usually frightening for our junior doctors. The following comments illustrate their feelings and concerns at the start of the traineeship:

"I think I will be useless here, since there is nothing to do."

"During training we are taught to deal with success and to apply scientific evidence and technological advances to solve medical problems. Such subjects as pain, suffering, and death are almost ignored, as if they don't represent important elements of daily medical practice."

"At medical school, I had few contacts with death, and when it occurred it was in artificial circumstances, where doctors I considered more capable commanded the scene. But everything was done with that same detachment they had always tried to transmit to us as being the only attitude suitable in such situations. Personal feelings were not allowed, and I felt that something was missing."

"I panic just thinking that I will have to see terminal patients. I won't know how to behave."

"I don't know what to do if the patient asks me 'Am I going to die?' or 'Doctor, when am I going to pass away?'"

### Cultural context

The first consultation with a patient can be discouraging for residents and students, as patients often seem

unaware of their actual medical state. This occurs for several reasons. Patients might not have been well informed about their condition. They might be in denial. Sometimes patients pretend not to know about the extent of their disease to protect their relatives, because they believe that their relatives mustn't, in any way, realize that they are suffering. At other times, patients and family members seem to have made a pact that dying and death are forbidden subjects.

Such behaviour might seem inexplicable to people living in countries other than Brazil; it results from the characteristics of our culture, very different from those of cultures in which the whole truth must be told, regardless of the situation. In our country, it is often necessary to use metaphor or to tell the truth slowly, over time.

Given this context, residents often initially have difficulty broaching complex issues with their patients. This difficulty can be challenging to overcome without good preparation and encouragement to

spend time on reflection. During orientation, residents read literary works and scientific papers that introduce various themes (eg, pain, suffering, dying, and death) and various points of view. They are also introduced to the principles of narrative medicine, a method we have found to be of great value in palliative care.

### Therapeutic tool

Beyond the technical and pharmacologic support offered to patients, our clinic uses narrative as a didactic and therapeutic tool. Residents and students quickly realize that, when they listen empathetically to patients and their families, stories of chaos usually emerge. Many doctors would like to ignore these stories, which highlight questions that have no answers and can make doctors feel powerless.

By listening to terminal patients, we make them feel they are not alone. We allow them to transform their chaos stories into quest stories, in which their illnesses become teaching tools for all involved. Quest stories are stories of transcendence. When terminal patients find attentive listeners, they have opportunities to organize the chaos produced in their lives by

When there is  
apparently nothing  
to do, one can  
still listen

incurable illness and find meaning that allows them to accept life unconditionally.<sup>1</sup>

This approach has motivated the creation of many stories in our clinic during the past 3 years: stories told, written, and rewritten by patients, students, patients' family members, doctors, and residents. The feelings, interpretation, and point of view of each participant in a story influences the way he or she will present it. Storytelling is a tendency deeply rooted in the core of human beings,<sup>2</sup> and patients are key storytellers.<sup>3</sup> When health professionals listen to their patients with empathy and compassion, they participate in the creation of a new script—one with elements of overcoming and transcendence, demonstrating that the course of the story was changed.

### Didactic tool

In the box below is an example of a narrative written by a group of residents during their palliative care rotation. The text illustrates a patient's journey from a chaos story to a quest story. This change was possible because, by being listened to and feeling himself understood, the patient became aware that he did not have to walk alone. He could finally talk about his feelings, doubts, and fears, not only to the team, but also to his wife.

The residents confessed that, before this story, they were not certain that they could help patients in their journey from suffering to transcendence. After reading the initial recommended articles, one resident had commented, "Maybe that is a theoretical idea, only a romantic vision of some authors." As time passed, however, the residents experienced other situations that enriched their clinical practice and stimulated reflection—which made them feel like better doctors. They rewrote many stories and understood an important lesson: when there is apparently nothing to do, one can still listen.

After such experiences, the students and doctors often need to share narratives and to tell their own stories in order to transcend chaos into quests of their own. After a discussion related to the technical aspects of consultations, rotations in the clinic are closed with a session of reflective writing.<sup>4</sup> Literary texts or scientific papers related to the situations are discussed.

We have found that the narrative approach used in palliative care has been a good didactic and healing tool that enriches practice and is consistent with the precepts of family medicine.

### Understanding the hidden meaning

Mr João (a fictitious name) arrived in a wheelchair, which was being pushed by his wife, Mary (a fictitious name). He was very thin, pale, and crestfallen. Mary also looked downcast, but she started talking because her husband was silent. She gave us

a referral letter, which stated that João had nonresectable esophageal cancer. No further treatment was possible. He was being fed with a nasogastric tube. Looking at us with complicity, and maybe hope, she told us that her husband could not eat or sleep. He just kept coughing all the time. When he could murmur something, it was to complain about his pain. All parts of his body ached. And he drooled continuously.

And what could we do, we simple first-year residents? We wanted to run away. We felt a profound sense of powerlessness. Here was an actual chaos story. But someone had told us that, when there is apparently nothing to do, one can still listen. Yes, listening to Mary and trying to understand the hidden meaning of João's speechlessness was a good start. So, after taking some deep breaths, we started doing that. Mary told us about her life and about her relationship with João. She was very tired because she also had to take care of her mother, who had Alzheimer disease. But she was doing her best because João had been an excellent partner. They had been together for 8 years, and João had taken care of Maria when she was going through a difficult period of her life—she had been rejected by her first husband. They had enjoyed a good life since. They would have liked to have had children, but Maria had had a surgical tubal sterilization in her first marriage and was 40 years old at the time of the second marriage.

Realizing that, finally, someone was paying attention to him, João whispered some questions during the physical examination—the answers to which he certainly knew. "When am I going to speak again?" "If I get better, stronger, would it be possible to remove this cancer?"

When we spoke alone to Maria, she told us no doctor had directly told João that he was a terminal patient, but she knew that he had understood the truth by himself. Even so, sometimes he dared to have hope.


They left with a prescription for some medicine and information to help control João's symptoms. Dexamethasone was included in the prescription as a good option for controlling his severe cachexia, fatigue, and anorexia. We could see some relief on their faces when they said goodbye.

At the second meeting, João arrived walking, looking better. He was very pleased with the effect of the medication. Because of the apparent good results of the treatment, he seemed to have hopes of becoming well again. We explained to him we could not tell how long he would stay with us. Even if healing were impossible, however, we were at his side to make him feel as well as we could.

At the third encounter, the clinical situation remained the same. But we had news: Maria thought she was pregnant. She had symptoms and her abdomen was enlarging. Because of her age and past sterilization, the gynecologist thought Maria had fibroids and was undergoing menopause. She hadn't been able to have any tests because she was spending all of her available time taking care of João.

By the next meeting, she still hadn't had any tests, but Maria was certain she was pregnant. João remained stable, and we could perceive a seed of spirituality developing. Every day, he spent some time listening to a religious radio broadcast that gave him great serenity and acceptance. The medications were still effective. Sometimes dexamethasone seems to work miracles.

At each encounter, the links between residents, doctors, family, and patient were enhanced. We felt we were actually doing something useful, and João and Maria were very different from the first time we saw them. The most important thing that we were doing was just listening to them. They told us about their past, their feelings, and their needs. João had certainly been a jovial fellow.

Then one day, 4 months later, Maria appeared alone. She was crying when she said, "Doctors, he passed away. He had pneumonia, and I took him to the hospital because he was having trouble breathing. After 4 days at the hospital, he died. But he was at peace. Before that, though, the pregnancy was confirmed. So, João left us with the certainty that one part of him will be with me forever. The morning he died, he was listening to the priest he had so enjoyed at the end of his life. After the broadcast, he looked at me and said that he loved me. Then he pulled away the nasogastric tube, saying that he would not need it any more. He asked me to thank all of you who helped him along in those difficult days, kissed me, and said goodbye, telling me he would take care of me and our child from the other side." 

**Dr De Benedetto** is Coordinator of the Brazilian Society of Family Medicine's (SOBRAMFA's) Department of Humanities in São Paulo, Brazil. **Dr de Castro** is SOBRAMFA's third-year family medicine resident, **Dr de Carvalho** is SOBRAMFA's second-year family medicine resident, and **Dr Sanogo** is SOBRAMFA's first-year family medicine resident. **Dr Blasco** is SOBRAMFA's Scientific Director.

#### Competing interests

None declared

**Correspondence to: Dr De Benedetto, SOBRAMFA, rua Das Camélias, 637, São Paulo, 04048-061, Brazil; telephone 55 11 5583 3539; fax 55 11 5589 7678; e-mail macbet8@uol.com.br**

**The opinions expressed in commentaries are those of the authors. Publication does not imply endorsement by the College of Family Physicians of Canada.**

#### References

1. Frank AW. Just listening: narrative and deep illness. *Fam Syst Health* 1998;16:197-212.
2. De Benedetto MAC, Blasco PG, de Castro AG, de Carvalho C. Once upon a time ... at the Tenth SOBRAMFA International and Academic Meeting, São Paulo, Brazil. *J Learn Arts* 2006;2(1):7.
3. Frank AW. The standpoint of storyteller. *Qual Health Res* 2000;10(3):354-65.
4. Bolton G. Stories at work: reflective writing for practitioners. *Lancet* 1999;354(9174):243-5.

