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18 – Dealing With the Terminally Ill Patient: Use of a Reflective Group for Improving Students Experiences

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In ancient times, there were the doctor-priests or shamans, extraordinary people who established special relationships with those who were ill and practised medicine. Today, there are still a few of them, which, although almost forgotten in their isolated communities, still provoke great interest among anthropologists. Shamans of all ages and places have led sick people to a magical and mysterious scenery where the healing process is possible. After experiencing their healing journeys under the supervision of shamans, people have usually come back changed (1). However, the role of shamans is not just to cope with life and healing processes. Perhaps, their greatest ability is to deal properly with death. Therefore, they also fulfil the important purpose of helping their patients to die in peace and leading them to the other side of the veil.

Nowadays medicine is dominated by specialization, technology, and scientific evidence. The patients are seen in a fragmented way. This model offers uncountable advantages and was responsible for the abolition of great part of human suffering due to diseases and trauma. Yet health care professionals and patients are not wholly satisfied because they feel that some things are missing (2).

One of those missing things is the naturalness in dealing with issues related to death and periods of ending of life as that experienced by shamans. For example, the first encounters with terminal disease are usually frightening for medical students and junior doctors. This fact was observed once more in an academic palliative care ambulatory free clinic in Brazil where we worked for four years as the family doctors that supervised residents of family medicine and medical students. At first, they demonstrated great difficulties in developing a satisfactory patient-doctor relationship with terminal patients.

Some reasons of these difficulties were identified. At the first visit, most patients seemed unaware of their actual medical state. They might not have been well informed about their condition. Some of them might be in denial. Other ones pretended not to know about the severity of their disease to protect their relatives. For them, the ideal was that their family members didn't realize they were suffering. Sometimes relatives and patients seemed to have made a pact that dying and death were forbidden subjects. Certainly, such behaviour results from characteristics of our culture in which it is customary to tell the truth slowly, over time, through metaphors. Before such situation, residents and medical students became immobilized and did not know how to behave (3).

To overcome this challenge, a good preparation and encouragement to spend time for reflection were needed. That preparation took place by reading literary works and scientific papers that discussed topics as pain, suffering, dying and death, which were discussed from various points of view. Beyond that, residents and medical students were introduced to the principles of narrative medicine (4), a model we have believed to be essential in palliative care and a narrative approach was adopted.

The basic recommendation was listening to patients and relatives' stories with compassion and empathy, even those unrelated to their clinical histories, and paying attention to their beliefs and personal paradigms. In doing so, medical students and residents soon realized that narratives reinforce and enrich the doctor-patient relationship, create a positive outlook on diagnostic and treatment procedures and provide a clear understanding of the real needs of patients and families. They also learned that, in a palliative care setting, chaos stories usually emerge. Stories of chaos often cause reactions such as ignoring them or run away from them, because they highlight questions that have no answers and make doctors feel powerless (5). In such stories, there is no apparent order in the sequence of events and they report situations where there is no solution, except listening (3).

And by listening and acting as a compassionate witness for terminal patients, we made them feel they were not alone. This way, they were able to organize the chaos produced in their lives by incurable disease and to find a meaning that allowed them to accept suffering with honour and life unconditionally. So, their chaos stories were transformed into quest stories, which are stories of transcendence (5).

Over time, all members of the team followed and took part in many patients' stories, thus witnessing their journey from chaos to transcendence. An usual script was the progress of patients who arrived in a denial, depression or revolt phase and that, some months later, died peacefully in an atmosphere of love and acceptance. Important lessons were assimilated day by day.

After such engagement, students and doctors experienced their own chaos stories and also felt the need to share narratives in order to transcend chaos into quest stories of their own. Thereupon, after patient care and a discussion related to technical aspects of consultations, the weekly activity was closed with a reflective writing exercise in which we could share our personal narratives and talk about feelings, fears, hardships, insights and apprenticeship. Difficult situations were illuminated by literary texts or scientific papers related to them. Such informal meetings were essential to promote the reflection that made all the difference in that scenario of palliative care.

Our activity at the clinic lasted for four years but the lessons apprehended will persist forever. The adopted approach motivated the creation of many stories: stories told by patients, doctors, medical students and patients' family members, stories that were written and rewritten to become source of apprenticeship. It was clear that feelings, interpretations and points of view of each participant in a story influences the way he or she present it (3). The same story is told and interpreted in different ways by different people.

The narrative approach used in our palliative care ambulatory clinic was responsible for many learnings, which were shared among members of the team and through articles in medical journals. We confirmed, for example, that storytelling is a tendency deeply rooted in the core of human beings and patients are key storytellers. Especially at the stage of ending of life, people need to tell their own story, as if they wanted rewriting their lives. When there is apparently nothing to do, one can still listen. By listening to their patients with empathy and compassion, health professionals participate in the creation of a new script – one with elements of overcoming and transcendence, demonstrating that the course of the story was changed. Thus, even if the end of a story in palliative care is always the same - the inexorable death - its course can be changed.

The reflective process inspired by narratives and occurred over the years has shown us that it is still possible to recuperate some abilities of shamans. One of them is to deal properly with death and help our patients to die in peace. Another one is to pay attention to the possibility that certain therapeutic procedures acquire a symbolic efficacy, which is responsible for outcomes that exceed those resulting from the usual measures based on the exclusive application of the biomedical model. We believe that a narrative and reflective approach could promote the practice of medicine in an efficient and comprehensive way – as science, art and magic (1).

Take Home Message

- Especially at the stage of ending of life, people need to tell their own story, as if they wanted rewriting their lives.
- When there is apparently nothing to do, one can still listen.
- Good preparation and to spend time for reflection is needed to deal properly with terminal patients.
- By listening to their terminal patients with empathy and compassion, health professionals participate in the creation of a new script and collaborate to change the course of the story.
- Even if the end of a story in palliative care is always the same - the inexorable death - its course can be changed.

Original Abstract

<http://www.woncaeurope.org/content/3924-dealing-terminally-ill-patient-use-reflection-group-improving-students-experiences>

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