

# Teaching Palliative Care in a Free Clinic: A Brazilian Experience

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## 1. Introduction

There is no curricular palliative care teaching in Brazil. Brazilian's doctors are not training to deal with terminally ill patients.

We believe that we can teach some important skills using palliative care. Some essential topics that students can finish medical training in Brazil, without any formal contact. We can provide different approach in communication's skills by teaching in a palliative care setting.

In our group, Brazilian Society of Family Medicine (SOBRAMFA), we diced to create a palliative care setting. Our main objective was to observe students and residents and try to identify how this experience can influence their medical training.

The ideas presented here are the final result of a qualitative analysis about the students and residents' experience. We used the stories related by them to exemplify what they learned.

## 2. An overview of palliative care

Palliative Medicine is an ancient practice. Some centuries ago the only thing that doctors could do was palliative care (Melo,2003).

Palliative comes from *palliare*, a Latin term that means to cover, to decrease difficulties, exactly what medicine was.

An example that shows us how the intention to care and relieve people of suffering can be transformed in science is this description from Ambroise Paré, a barber-surgeon from France in 18<sup>th</sup> century. It was accepted practice at that time to pour boiling elder oil on an amputated limb to cauterize it and keep away "bad humors". As a military barber-surgeon operating in the Apennine Alps, Paré saw hundreds of patients a day. One night, in the thick of battle, he ran out of elder oil and had to devise a salve of egg, oil of rose, and turpentine. The salve he applied was soothing and causes his patients no pain. The next morning, half the patients treated with elder oil were dead and the other half in agony while all his patients treated with the salve were resting peacefully and healing well. When he saw his new treatment worked more effectively and caused less pain to his patients, Paré would not change his methods (Helliwell,1999).

In the beginning of 20th century William Osler, a famous doctor at that time, was the first scientist that wrote about palliative care. The patients and doctors used to correlate suffering with the end of lifetime and Osler tried to change this idea (Irigoyen,2002).

Osler was a general practitioner, he was considered the smartest, the best one in his time;. His diagnostic ability was fabulous. The title of his biography written by Reid is "The great doctor". It's amazing that in a time where there weren't efficient therapeutics like today, Osler became a healer. It seems that his secret was to know people, not just diseases. He could understand human suffering and he respected that. He tried to understand more than physical and chemical diseases consequences, to be able to share feelings and spiritual thoughts. He was an optimist and had a big compassion. His relationship with patients was a kind of religious thing. Osler blessed them and they got better. He used few drugs and didn't believe in many therapeutic methods. But he believed in human being. He always treated patients well and transmitted security to them. He believed in "bed medicine" (Relman,1989).

Cecily Saunders in 1960 developed the principles of modern hospice and palliative care. She heard patients and learned with them their real necessities deciding to dedicate her life to care of terminally ill patients. Saunders started a "hospice" called Saint Christopher's Hospice, in London (Figueroedo,2003; Melvin,2001; South-Paul et al, 2004 ). She emphasized excellence in pain and symptom management; care of the whole person including their physical, emotional, social and spiritual needs; and the need for research in this newly developing field of medicine.

She used to say to her patients "You are important because you are unique. You will be important to us until the last moment of your life, and we will make everything we can, not just that you die in peace, but that you live until your death moment" (South-Paul et al, 2004).

Nowadays, this philosophy is present in a lot of countries and in many palliative care services.

In 1968, Dr Elizabeth Kuebler-Ross, a psychiatrist working closely with terminally ill people in the United States, published her seminal work, *On Death and Dying*. This book, for the first time, described the psychological crisis of the terminally ill person in terms of defined stages -denial, anger, bargaining, depression, and acceptance. This book has since become essential reading for clinicians who care for the terminally ill. She was the first to show the needs of dying, stressing the need for personal autonomy, death with dignity, and the benefit of death at home versus in a health care facility (Melvin,2001; South-Paul et al, 2004).

## **2.1 Palliative education setting**

Human suffering and death are real facts in daily doctors' activity. In spite of that, we still observe a big lack of professionals that are properly trained and prepared to deal with this subject (Blasco, 1997).

Death is a phenomenon that disrupts medical practice. It is not uncommon that doctors don't consider death as a real possibility. Death is not some unhappy fact that comes and

makes the doctor's brilliant acting more difficult. Nowadays we can find doctors that use high-level technology but, in some way, give up their incurable patients, with whom their technical knowledge doesn't work. They are doctors for "new cars", "runners for short running". They are unable to remain comfortable in situations where purely biomedical technical skills are not enough (Blasco, 1997).

Experts agree that experimentally based and developmentally appropriate ethics education is needed during medical training to prepare medical students to provide excellent end-of-life care ( Ahmedzai, 1982; Billings & Block , 1997;Caralis & Hammond , 1992; Lloyd-Williams & MacLeod, 2004 ).

In U.S. a survey had demonstrated that the majority of medical schools do not provide palliative care knowledge during graduation. The researchers suggested the implementation of palliative guideline in medical curriculum (Aalst-Cohen et al, 2008)

## **2.2 Suffering and death: Palliative care**

Palliative Medicine is the study and management of patients with illness in which cure is no longer possible and an end point of death is expected within a finite period of time. The focus is on the control of symptoms and maximizing patient' self-defined quality of life (Melvin,2001; Rakel,1995). The complex goal of relief suffering can't be one-dimensional but must include the four human dimensions of human experience: physical (pain, dyspnea, cough, constipation, delirium), emotional (anxiety, depression, grief), social (financial concerns, unfinished business) and spiritual (guilt, sadness, worthlessness). To provide this complete assistance the palliative care is usually made by an interdisciplinary team (Melvin,2001; South-Paul et al, 2004).

According to World Health Organization, palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten or postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death;offers a support system to help the family cope during the patients illness and in their own bereavement; uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated; will enhance quality of life, and may also positively influence the course of illness; is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications

## **2.3 Family medicine and palliative care**

The reason to have a family doctor in a palliative care service becomes clear if we understand the principles of family medicine.

Family Medicine's focus and action fields are: primary care, medical education and leadership. Trained in a specialty that is focused on person, the family physician is a person's specialist (Blasco et al,2003).

Irigoyen says that the Family Medicine participation on palliative care occurs because both specialties focus on continuity care, prevention and family dynamics study.

Family Medicine's philosophy promotes doctors that have as a professional objective to improve health and quality of life of their patients in a broader sense. The doctor-patient relationship doesn't end with some incurable and deadly disease, even with the patient's death, as the relationship with the family goes on after that (Irigoyen,2002).

To provide this kind of care to patients with cancer, a palliative care outpatient clinic started on March 2004 after an agreement between the oncology department of ABC Medical School in Santo André (Brazil) and the Brazilian Society of Family Medicine (SOBRAMFA).

This ambulatory gives medical assistance to patients that the oncologists consider out of traditional therapeutic possibilities. The objective is to training doctors in skills necessary to provide this kind of assistance.

### **3. Methodology**

Students and residents consult terminally ill in a free clinic that provides medical assistance to patients who are referred by oncologists. In the setting the learners are orientated to the principles of palliative care, narrative medicine and have required readings related to these issues. A reflective writing session, in which patients' stories and doctors' and students' feelings and concerns are shared in a narrative perspective, closes the ambulatory day.

A structure interview was used after nine months of work to express the doctors' reflection clearly.

About the palliative care ambulatory:

- What was the most important aspect for you?
- In which way did this ambulatory experience contribute to your training as a future doctor?
- Did you have any negative experiences?
- Which was your best experience?
- Please write down a patient's story that has drawn your attention.

#### **3.1 Objectives**

Identify the educational impact of palliative medicine in family medicine training.

#### **3.2 Setting**

In 2004 the Brazilian Society of Family Medicine (SOBRAMFA), in partnership with the oncology department of ABC Medical School, created a Palliative Care Ambulatory Clinic (PCAC). The PCAC is a free clinic that provides medical assistance to patients who are referred by oncologists. The clinic takes place once a week and is staffed by family physicians, residents, and medical students.

Family members are usually present at the encounters, but both patients and relatives have the opportunity to talk individually to members of the team.

At the end of each day, a reflective environment is created. So, students, residents and faculty take part in a reflective writing session in which the patients' stories, doctors' and students' feelings and concerns are shared in a narrative perspective.

Our study analyzes a period from March to November 2004, where we had 37 patients (22 men; 15 women) and 24 of them had died.

### **3.3 Analisys**

We decided to look at the educational impact of the PCAC using a qualitative method of thematic analysis. The research had the approval of SOBRAMFA's Ethics Committee.

Data was collected from three sources: a journal composed by the preceptors who acted as participant observers, a questionnaire given to the residents and students at the end of their rotation, and the reflective papers written by students and residents.

The teachers that participated in the PCAC, individually, did an analysis of this material and list some topics. After five discussion meetings they decided by tree different topics: keep the focus on the patient, learning to deal with families and from fear to comfort.

## **4. Findings**

### **4.1 Keep the focus on the patient**

Palliative care patients usually have a lot of symptoms, either caused by cancer, like pain and fatigue, or non related to it, like headache or hypertension.

The learners had chances to diagnose and treat some symptoms or diseases that were not so visible in the first contact.

It is important to note that every family doctor during his/her professional life will likely need to offer palliative care to his/her patients, and this doctor has to be able to do so.

#### **4.1.1 What bothers the patient?**

"Mr. J comes to palliative care ambulatory because of a liver cancer (without confirmation diagnosis). It was all we knew about him, besides that he hadn't had a good treatment response. After some conversation he told us that what was really bothering him was a sinusitis that nobody had treated before. So we gave him some general orientations and focused treatment on his respiratory problem. His cancer was under control, and after our intervention he had an improvement in his respiratory symptoms. In the following visits he would breathe deeply several times to show us how better he felt."

#### **4.1.2 Can we always do something for our patients?**

*"One of the most significant patients was Mr. J, a middle aged man who had a larynx tumor, tracheotomy, cachexia, radiotherapy complications and a lot of pain even with morphine in high doses. At first sight he looked like an untreatable patient, and many doctors and family members had*

*abandoned him. When we listened to his needs, we realized the possibility to improve analgesics to better pain control using amitriptylin and carbamazepine, which worked well. The orientations to offer food in small quantity several times during the day, about intestinal habit and wound care made possible a better pain control and a more comfortable end of life. The family members felt more comfortable too and realized they could do something for the patient's comfort. There is no doubt those doctors' care and family love made the difference for the patient who never missed one consultation not even in the last days of his life."*

About the ambulatory context one of the doctors wrote: "Any time the team is trying to release suffering and make something to the patient with the family help. Even if nothing more can be done clinically, we can help the patient feel that he has not been abandoned and that somebody still cares about him".

#### **4.1.3 How do I take all these medications, Doc?**

"In his first consultation Mr. J, 65 years old, with a larynx cancer (already treated), hypertension and hypothyroidism after radiotherapy, brought a bag with his medications. We discovered that he couldn't read which makes it difficult for him to know how to use all that. A colorful table and the identification of the medication was enough to him to learn how to do it."

### **4.2 Learning to deal with families**

The families have an active participation in this end of life stage and need orientation about nutrition, hygiene, sadness, suffering and death.

The residents and students could understand the importance of setting opportunities for family members to talk about patients' feelings and about their own feelings and difficulties.

"It is necessary to spend additional time with family members. As a result of that special attention, they can provide better care to the patient at home." Residents and students noticed that even when patients had difficulty visiting the office, the family would still come.

Some family members would express their gratitude through letters, calls, or even visiting the clinic after the patient's death. Occasionally, they came back because they had a need to share experiences and feelings from the patient's final moments.

#### **4.2.1 Receiving news**

"It is obvious that the relationship depends on the family and patient. It is interesting to note that the family, perhaps, because of this intense participation in the patient care, feels comfortable to continue to visit us after the patient dies. In these months we had the opportunity to receive some calls, letters or ambulatory visits were the family express their gratitude and inform us about how the patient died. Difficult moments where we can notice that we were poorly prepared and trained during the medical school to deal with ours and patient's families' emotions and feelings."

"Mrs. L, 65 years old, had a huge stomach adenocarcinoma that provoked massive ascites. She was not having dyspnea that day, but her two daughters were worried about her ascites

and told us that the procedure made to reverse that was not very efficient. They had a paper with a well-done description from medication and the time to take each one. They had come to us to relieve their mother's pain. We explained to them how to use morphine and other symptomatic medication, diuretics to eliminate the ascites, and gave them a cellular phone number to call if they needed. After that, the patient got better for a few days, but the ascites relapsed. She went to the hospital where they did another procedure and after that she got really worse and died some hours later. Next week, during our clinical discussion time, the receptionist told us that the Mrs. L daughters were there to talk to us. They had come to tell what had happened in their mother's last moments and thanked for what we had done for their mother."

#### **4.2.2 What can I give him to eat?**

"The families have a lot of doubt about nutrition, even in patients without tubes. We saw a son that wouldn't let his mother eat ice cream because he thought that she could get cold and wives that didn't offer a typical Brazilian food twice a week because it is very spicy. We had noticed with time that it is very important to tell family members what they can give to the patient and how to do it. Patients felt better because they had something like a "medical authorization" to eat what they wanted."

#### **4.3 From fear to comfort**

The first contact with a terminal disease was usually frightening for our residents and students. "I think I will be useless here." "During usual training we are taught to solve medical problems. Subjects such as pain, suffering, and death are almost ignored, as if they don't represent important elements of daily medical practice."

"I panic just thinking that I won't know how to behave." Such reactions denote the lack of preparation to approach the usual issues related to terminal patients.

Nevertheless, step by step, trainees acquired more and more ability to deal with the issues they considered difficult. They realized that by listening to the patients and relatives it is possible to detect their real needs. "I could see that my patient did not want to be seen as a special person whose death is inexorable but as a patient like any other. He became calm when I listened to him with attention and was very satisfied with the prescription of the medicines." "Often, the solutions are simpler than we can imagine." "For me, this is something new. I saw the whole team trying to do their best to alleviate suffering and get the family involved in the care. I realized that, even if healing is no longer possible, we can help patients feel they are not alone because there is somebody with them, very interested in helping them."

#### **4.3.1 Do I have cancer, Doctor? Will you help me?**

"In the beginning I thought that this first question would be frequent, but because of the advanced disease's stage most of the patients knew what was going on.

The second question is the most common question in the ambulatory setting. Sometimes patients think we are their last hope, someone that can improve their condition. This

question is very hard to answer, because we will try our best to each one, even knowing that, almost ever, we will be unable to do something clinically for them.

We have a strange feeling like "I don't know if I want to return to the room and finish the consultation". Maybe because of those feelings the discussion with all the team is more important in this place. It's not just the clinical decision but how to communicate with the patient that matters. "Remember that is always useful to repeat information to the patient and family and try to find little solutions that can make a big difference to the patient's comfort. It helps to learn how to face consultations in a different way, with other kinds of expectations."

## 5. Discussion

The PCAC provided a unique training apprenticeship for medical students and residents. They learned specific issues, like pain control, and had the opportunity to discuss about aspects of caring for dying patients.

Medical students usually do not learn how to deal with feelings that emerge when they are with a dying patient. On the contrary, they are told to keep a certain distance from the patient and their relatives (Hennezel & Leloup, 2000).

Realizing that this kind of attitude is not helpful, the trainees were receptive to the new approaches that we presented. They were able to face death, pain, and suffering as natural as possible. Events that are part of human life, without losing a respectful attitude.

Students learned that when doctors act with goodwill, humility, compassion, and honesty, patients and their families always benefit (Taylor et al, 2003). Residents learned that family physicians need skills in palliative care since they frequently encounter dying patients. They realized that family members play an important role in a patient's end of life period and must also receive support.

The outcomes described were, in some way, consequence of the application of a narrative approach at the PCAC. By listening to terminal patients with empathy and compassion, we can make them feel that they are not alone, a frequent sentiment in this kind of patients. When they meet an attentive listener and have the opportunity to organize the chaos in their life and to find a meaning in which their illness becomes a teaching condition for all involved.

The students learned that when, apparently, there is nothing to do, we can still listen. The journal writing (De Benedetto et al, 2007) were effective in promoting reflection and it is an excellent tool for dealing with chaos stories. Writing in prose or poetry to express feelings that we have difficulty dealing with can have healing effects.

The medical educators noted a necessity of the importance to teach palliative care and are trying to improve this in medical school. There are evidences showing that the lack of palliative care training can be negative to doctors and patients. For example, an ineffective doctor-patient communication can affect the patient's satisfaction (Torke et al, 2004).

The barriers for an adequate care are from three types: no specific training, personal attitudes against death and political disinterest (Irigoyen, 2002). So, this kind of initiative can help in this improvement in medical education.

## 6. Conclusion

The students' experiences were essential to promote reflection about difficult themes and to break barriers that prevent them from dealing properly with terminal patients. Our learners had the opportunity to learned how to manage terminal patients in a holistic way.

The technical knowledge provided in Palliative Care Ambulatory Clinic alliedto the creation of an ambiance propitious to reflection, made it, in an educational way, a unique setting to a continuum learning. The idea that palliation is a failure of treatment was quickly abolished.

This activity should be maintained and expanded to other didactic Palliative Care settings as hospice, hospital and home care.

The results of these preliminary evaluation became a stimulus for expanding the Palliative Care Program in Brazil.

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