

## ABSTRACT

Usually the foundation of the St. Christopher's Hospice in London in 1967 by Cicely Saunders is recognized as the beginning of modern palliative care. Since then, palliative care has spread all over the world. In Portugal palliative care began in 1994 with the opening of the Continuing Care Unit at the Portuguese Institute of Oncology (IPO) - Porto. Nowadays, palliative care is the standard of treatment for patients with advanced and progressive chronic diseases and can also be used alongside "curative" treatments.

Palliative care began because of the problems of patients with advanced cancer; but today there is a consensus about its potential usefulness independently of the type of underlying chronic disease. However, it remains the case that oncological patients continue to make up the greatest number of people referred to palliative care.

Most patients with chronic diseases have multiple problems due to their disease and sometimes also to the treatment they underwent previously. Furthermore, patients admitted to palliative care arrive with very different conditions in aspects such as consciousness, cognitive function, emotional state, performance, symptoms, etc. Patients may be very frail, frightened or anxious. There is also the problem of the work that a busy team has and the time available to each patient. Therefore, an extensive evaluation might be impossible and can be also a burden for the patient. However, to help the patients the main problems should be identified rigorously. Other problems can be addressed later if appropriate.

To respond to the variety of situations explained above an integrated system for the initial evaluation of the main problems of oncological patients was developed which can adapt to those diverse circumstances. The system should be seen as a screening method, as the problems detected need to be assessed further in their characteristics and causes if they are to be solved.

The elements of the system are presented in four of the chapters of this thesis:

- a. In the chapter Communication we try to demonstrate the need and the wish for information that most patients feel and the difficulties they often have to obtain it with two studies concluded some years ago in the IPO - Porto which have already been published. We try to show the need to match the information disclosed to patients' wishes without following rigid principles, but following the patients' will and rhythm;
- b. In the third chapter the method to assess consciousness is described at the wakefulness and the content levels. To assess wakefulness a scale was developed, which has been published. To assess the cognitive function in those patients with a wakefulness level allowing interaction, the Confusion Assessment Method was included because it was already in use in the Palliative Care Unit of the IPO - Porto and because it was recently validated in palliative care and in Portuguese;
- c. In the fourth chapter a tool developed with the Delphi method, involving international experts, for the assessment of patients without cognitive failure is presented. The tool includes 10 symptoms, a question about the patients' capacity for self care, a question about social issues and a general question about the evaluation that patients do about their own well-being;
- d. For those patients who cannot be assessed directly because of cognitive failure two methods were studied that are described in chapter 5. The method with the better results was the general evaluation of signs of discomfort. Even so, its sensitivity was relatively low (40%); although its specificity was very high (97%) as was the positive predictive value (86%).

The general mode of functioning of the system is the following:

- 1 • If the patient were obviously suffering (eg. uncontrolled pain) making it inappropriate to pursue the assessment:
  - a. Control its cause:
    - i. The assessment may not be pursued at that time because the problem is difficult to solve or the side effects of the treatment do not allow it (eg. somnolence caused by an opioid).
  
- 2 • If the problem can be controlled without problems at that moment or if there was no suffering which precluded the assessment:
  - a. Assess the wakefulness using the method included in chapter 3;
  - b. Assess cognition, if the wakefulness state allows it, using the CAM:
    - i. The assessment should be done while the patient is globally evaluated, looking for the problems included in the CAM.
  - c. Assessment of information needs if cognition is adequate:
    - i. This is a very important issue, but the delivery of information can occur at this or at another moment;
  - d. Assessment of the main problems if cognition allows it using the method indicated in chapter 4.
  - e. Assessment of the main problems, if cognition is abnormal not allowing the direct assessment, using the method indicated in chapter 5.

Although this method of screening has been developed for the initial assessment the problems of oncological patients admitted in palliative care, most elements of the tool can also be used in the everyday work routine. This system results from many years of team work and systematic clinical research. It seems to meet its aim and probably can be used in other clinical settings. However, it should be continuously improved.