

an affected limb, we propose that it would be wiser to define the condition strictly in terms of the symptoms that are evident. For example, in the case referred to by Chahine et al., the diagnosis would be “painful lower limb edema with evidence of hyperalgesia, cause unknown, CRPS-like.”

At this stage, and in cases such as that referred to here, more cases should be accumulated and thoroughly investigated so that a more accurate syndrome profile can be developed and validated.

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### **Re: Palliative Sedation: The Need for a Descriptive Definition**

To the Editor:

In their review of the practice of palliative sedation, Claessens et al.<sup>1</sup> point out that many studies use different definitions for the practice of palliative sedation, most of which they consider too narrow. They plead for the common use of a single, clear-cut definition of palliative sedation to compare studies in a methodologically correct way.

We share the authors' views that the common use of a single, clear-cut definition will highly improve the quality and comparability

of studies that investigate the practice of palliative sedation. However, we disagree with their proposed definition: “The intentional administration of sedative drugs in dosages and combinations required to reduce the consciousness of a terminal patient as much as necessary to adequately relieve one or more refractory symptoms.” It is clear that this definition mixes descriptive language with criteria of due care: the use of sedating medications, proportionality, the patient being terminal, and the presence of refractory symptoms. We agree with Claessens et al. that it is of utmost importance to discuss and formulate criteria of due care for the practice of sedation. However, criteria of due care are normative and, as such, should not be part of definitions, but formulated separately, for example, in guidelines. By incorporating normative elements in a definition, moral discussions become obfuscated and the question is raised of what to call cases in which the same acts were performed but in which other medications, indications, or patients were involved. Generally speaking, the definition of an intervention should be descriptive, allowing for a separate discussion about the conditions under which this intervention would be morally acceptable. Only with a descriptive definition can valid comparable research be conducted in a methodologically sound manner. Therefore, we propose to define palliative sedation as “sedation in the last phase of life.” Additionally, we propose to distinguish and define one specific type of sedation, *continuous deep sedation until death*. This is morally more controversial because of its potential life-shortening effect, and, as such, it differs from “normal sedating practices,” such as sedation for providing temporary comfort.

The importance of using a descriptive definition is clearly illustrated by one of the results of the authors' review, namely, that in several instances, palliative sedation is not provided in conformance with suggested criteria of due care. To simply reject such cases as “not palliative sedation,” as the authors do, excludes those cases from evaluation, discussion, and potential improvement.

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### Authors' Reply: A Descriptive Definition of Palliative Sedation?

To the Editor:

We would first like to thank Rietjens et al.<sup>1</sup> for their comment on our review.<sup>2</sup> Indeed, one of the most important issues regarding palliative sedation is the issue of definition. We regret that in this response, we are only able to discuss, rather briefly, a few elements of this extremely complex issue.

Rietjens et al. disagree with our definition of palliative sedation, which we initially presented at the first European Association for Palliative Care (EAPC) research conference in Berlin in 2000,<sup>3</sup> discussed in several publications<sup>4,5</sup> (in detail in a 2002 book chapter in which we also discussed in depth the concept of palliative sedation<sup>6</sup>), and briefly mentioned in our review. Rietjens et al. prefer a descriptive definition that does not include normative elements and propose to define palliative sedation as “sedation in the last phase of life.”

It is, first of all, a conceptual misconception to think that there exists a non-normative

definition. Definitions are *per definition* normative. The Latin *definire* literally means to delimit, to determine boundaries. A definition decides what belongs to a certain category and what does not, and it is clear, of course, that often these decisions or choices are controversial and the subject of serious debate. Decisions or choices are never descriptive.

Regarding the alternative definition proposed by Rietjens et al., we can be fairly short. Their proposal can never be an acceptable definition, because it is not a definition at all. One simply cannot take an essential part (sedation) of the term to be defined (palliative sedation)—a part, moreover, that is clearly in need of clarification—and just reiterate it and call the result a definition.

In no way does our definition of palliative sedation exclude cases of “not palliative sedation” (palliative sedation that does not conform to our definition) from evaluation, discussion, and potential improvement. When gathering data, for example, by using questionnaires or interviewing people, one must, of course, be very careful with terms and definitions (and probably avoid them as much as possible). Secondly, as a researcher in this area, one is not only interested in “palliative sedation” but also in “not palliative sedation.” That is why our own large-scale empirical study on palliative sedation (submitted) actually studied any use of sedative medication in the palliative care units we worked with. This is, incidentally, very similar to what van der Maas and van der Wal did when, back in 1990, they were asked to map Dutch euthanasia practice. For evident reasons, they explicitly chose not to limit their study to euthanasia (though they continued to respect the strict Dutch definition of the term!), but to also map other “medical decisions concerning the end of life.”<sup>7</sup> Although we have several serious questions regarding this study (and subsequent studies in this line), they did have a point in taking a broader perspective. There is certainly no contradiction between using strict definitions (especially in the interpretation and discussion of the data) and conducting much broader research. And indeed, in this way, no cases are excluded from evaluation, discussion, and potential improvement. When a researcher, however, in his or her interpretation