

## Editorial

# Investigating euthanasia: methodological, ethical and clinical considerations

Discussions about euthanasia and how it may relate to palliative medicine are not straightforward. More complicated still is the search for sound empirical evidence to inform these debates. In this journal issue, two research studies, from the Netherlands and from France, examine this thorny topic. The first paper describes differences between patients who died after euthanasia had been performed and patients who did not request euthanasia,<sup>1</sup> and the second examines the demand for euthanasia in palliative care units using a prospective design.<sup>2</sup> These papers illustrate some of the methodological and ethical issues that must be assiduously traversed when navigating this difficult area of research.

The paper by Georges *et al.*,<sup>1</sup> 'Differences between patients who died after euthanasia had been performed and patients who did not request euthanasia', examined data from a survey of physicians conducted in the Netherlands in order to address whether better palliative care might decrease patient interest in euthanasia. Terminally ill cancer patients who died after their request was granted and euthanasia was performed were compared, along a number of axes, with terminally ill patients who did not request euthanasia. The researchers reported that the prevalence and severity of certain symptoms (e.g., pain, nausea) were higher in patients who died after euthanasia. The prevalence of certain psychiatric problems was lower. The authors concluded that no differences in symptom treatment or care provided were apparent between the two groups.

This is an important research question that can only be addressed within the environment of the Netherlands and offers an opportunity to inform thinking regarding clinical and policy direction in other countries. Therefore, the authors make a valuable contribution.

However, it is also the case that the entire results of this study could be due to selection. That is, the patients who received euthanasia were seen to be suffering from worse symptoms and to be of sounder mind than the patients that did not; but, of course, these are requirements for receiving euthanasia in the Netherlands. In a sense, it is possible that this study has simply confirmed that the

criteria for euthanasia specified in the Netherlands are being properly implemented. It is unclear whether the evidence really suggests that, if patients were adequately treated, they would not request euthanasia.

The authors themselves have identified a number of limitations that make comparisons between these two groups in their research difficult. First, the comparison involved a retrospective account of patients who had requested euthanasia with a prospective group of patients who did not. The time frames, memory recall biases and slight variations in the type of data collected are pertinent limitations that must be taken into consideration. The study also only compared patients who requested euthanasia and whose wishes were granted, and those who did not make such a request. No data were obtained from patients who may have made a request for euthanasia, but whose wishes were not granted. Another critical design decision associated with this type of study is the choice of who provides the information; in this instance, the data were provided by physicians, making it impossible to take the experience of patients into account.

Comby and Filbet's paper,<sup>2</sup> 'The demand for euthanasia in palliative care units: a prospective study in seven units of the Rhone-Alpes region', documents a prospective survey of five palliative care units in France over a six-month time period. The authors report a low frequency of requests for euthanasia (13 of 611 patients or 2.1%). The authors endeavour to identify reasons for the requests and staff responses to requests.

A number of methodological challenges surface in this type of study, highlighting reasons why this work is rarely undertaken and illustrating why interpretations of the results are difficult.

An important methodological issue involves the question of communication about a request for euthanasia. How does a researcher reliably determine if a request for euthanasia has actually occurred? How is the request made? What language is used? Who receives this request? Is the request accurately perceived or does some sort of social and emotional filter affect the message? The authors of this study attempted to include all patients admitted to a set of designated

palliative care services over a strict time frame. Requests from both patients and relatives were considered relevant to the study question. Information regarding the request was ascertained using a six-page questionnaire. The authors adopted a very inclusive approach, seeking a broad range of qualitative data regarding the language used, timing of the request, details regarding to whom the request was made and other such relevant information. This approach aims to ensure that relevant data are not missed and prevents application of preconceived categories/classifications that might be limiting.

A separate, and crucial, issue that was apparent to the editorial team when this paper was reviewed was the disclosure by the researchers that ethical approval for this study was not obtained. An ongoing discussion with the researchers ensued to clarify this point. The authors explained that, according to best practice in France at the time of this study, it was usual practice to obtain consent from the health care team to undertake the study. They further reported that studies of this nature would not normally be presented to ethics committees and would not involve informed consent by patients or their relatives.

In spite of the information provided by the authors regarding research practice in France, and notwithstanding the extent to which such procedures were followed or to which such procedures vary across time and place,<sup>3</sup> this matter raises important questions about how such studies might be undertaken. If there had been a requirement to obtain patient and family consent, as is usually specified by ethical review committees, would the study have achieved the same degree of disclosure? Could discussion of the purpose of the study with prospective participants be considered harmful? Is it possible that a creative design might have emerged that would have allowed a consent process whilst protecting patients and families from associated risks? This paper re-visits questions regarding autonomy and informed consent procedures and variations in cultural practices related to ethical approval.

What we have learned from this research is that the incidence of euthanasia requests is low. More importantly, this study documented important clinical observations regarding the timing of these requests and factors that are potentially associated with euthanasia statements. Factors such as physical changes, loss of social roles, existential distress, depression, pain and unrelieved symptoms are theoretically within the domain of a palliative care approach.<sup>4</sup> Stability of the patients' requests over time was also reported, confirming earlier reports<sup>5</sup> that patients may vary in their wishes for a hastened death over a relatively short time interval.

Of special importance is the identification of 'environmental factors' as pertinent to the requests for euthanasia. This study identified factors that may be triggers for family members in their requests/inquiries about euthanasia for the patient including family exhaustion, communication problems within the family and family conflict. Moreover, the presence of family factors may be particularly important in shaping the persistence of the patient's requests. These factors, although challenging to the palliative care team, are issues that warrant attention. Requests for euthanasia stemming from these types of family-related factors may be amenable to change and families who are helped to cope more effectively may find that there are other options than a euthanasia request.

In summary, both of these unique papers tackle new territory and have important limitations. These limits have been openly articulated so that the reader can consider the work in light of the methodological qualifications and ethical conundrums that are often found in this type of research. Studies of such a difficult topic as euthanasia can lead to statistically and ethically suboptimal research designs and uncertain results. However, these results raise important questions of a substantive and methodological nature and underscore the challenges for others in studying euthanasia. The questions raised in these two studies may prompt more reflective palliative care practice as we think hard about how we might respond with more specificity, purpose and energy to address issues of concern that may prompt these types of requests from our patients and their families. And they may promote more refined research approaches, seeking to address the methodological challenges and ethical requirements of clinical research at the end of life.

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