

## **Defining the patient population: one of the problems for palliative care research.**

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### **Abstract:**

There is a lack of clear definition and clear inclusion criteria in palliative care research. The aim of this study was to describe consequences of three inclusion criteria in the build up of different study populations, studied in terms of size, number of doctor\_ patient contacts and demographic characteristics. General practitioners received a questionnaire for all patients who died during the second Dutch National Survey of General Practice ( n\_ 2194), to determine whether (1) patients received non-curative treatment; (2) patients received palliative care; and (3) death was expected (total response rate\_ 73%). The criterion 'death was expected' included most patients (62%) followed by 'palliative care' (46%) and 'noncurative treatment' (39%). Similarity between the definition-based populations was fair to moderate. More 'palliative care' and 'death was expected' in patients who had cancer than 'non-curative treatment' patients. The conclusions show substantial differences in populations according to the different inclusion criteria used to select them. Future research in palliative care should acknowledge the limitations of using certain inclusion criteria and explore potential bias.

### **Comments:**

Strengths/uniqueness: This paper addresses the important issue of defining a palliative care population. By virtue of analysis alongside the Dutch National Survey of General Practice, the study is unique in that a large number of observations were obtained using a questionnaire. Finally, the sample was obtained from a primary health care setting and is therefore considered fairly representative of the population.

Weakness: The primary weakness is the ambiguity and brevity of the questions. For example "was the patient's death sudden and unexpected?" is ambiguous in that an affirmative response excludes the two categories sudden and expected or gradual and unexpected. Asking the question in terms of probability of death and probable lifespan would have been clearer. An extensive literature on the difficulty of obtaining an accurate prognosis however does not suggest an immediate remedy to this weakness.

More questions relevant to the domain of palliative care would have been helpful, particularly in the assessment of needs. A minor point – although the response rate was 73%, a lack of analysis of participation bias is a limitation in the analysis.

Relevance to Palliative Care: Relevance to research is self explanatory and has been well discussed in the literature. This paper is also of relevance to program planning and clinical practice in that questions are raised about populations with palliative needs who are not currently receiving palliative care.