

Knowledge and Experience about dying in our society



OPCARE9



A European Collaboration to optimise research for the care of cancer patients in the last days of life

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The integration of non-scientific literature as a control group for systematic review on phenomena in the last days of life

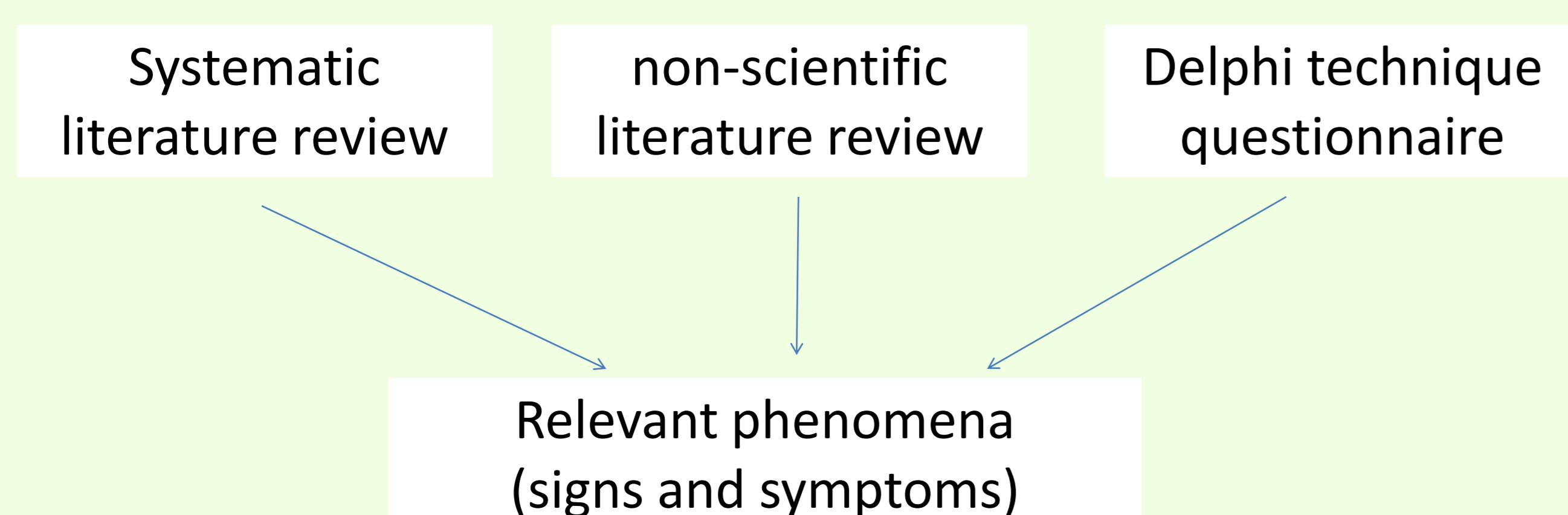
Initial situation:

The identification of phenomena of approaching death and its prognostic value are basic for diagnosing dying. Research during the last days of life remains ethically difficult and scientific data for signs and symptoms for diagnosing dying are consequently rare and questionable. While reviewing the literature on this purpose within the OPCARE9 activities, the question was posed:

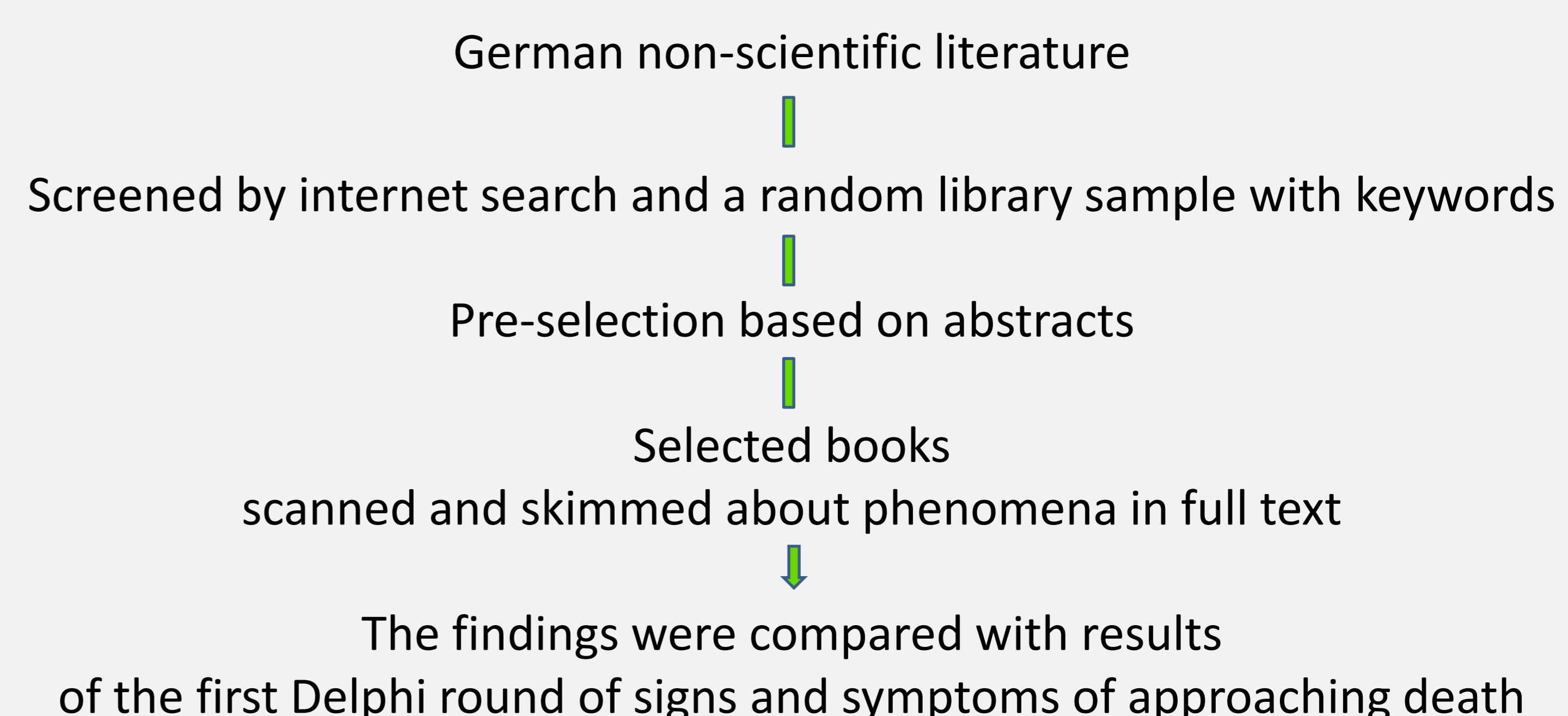
Question:

May the integration of non-scientific literature contribute more information in this situation?

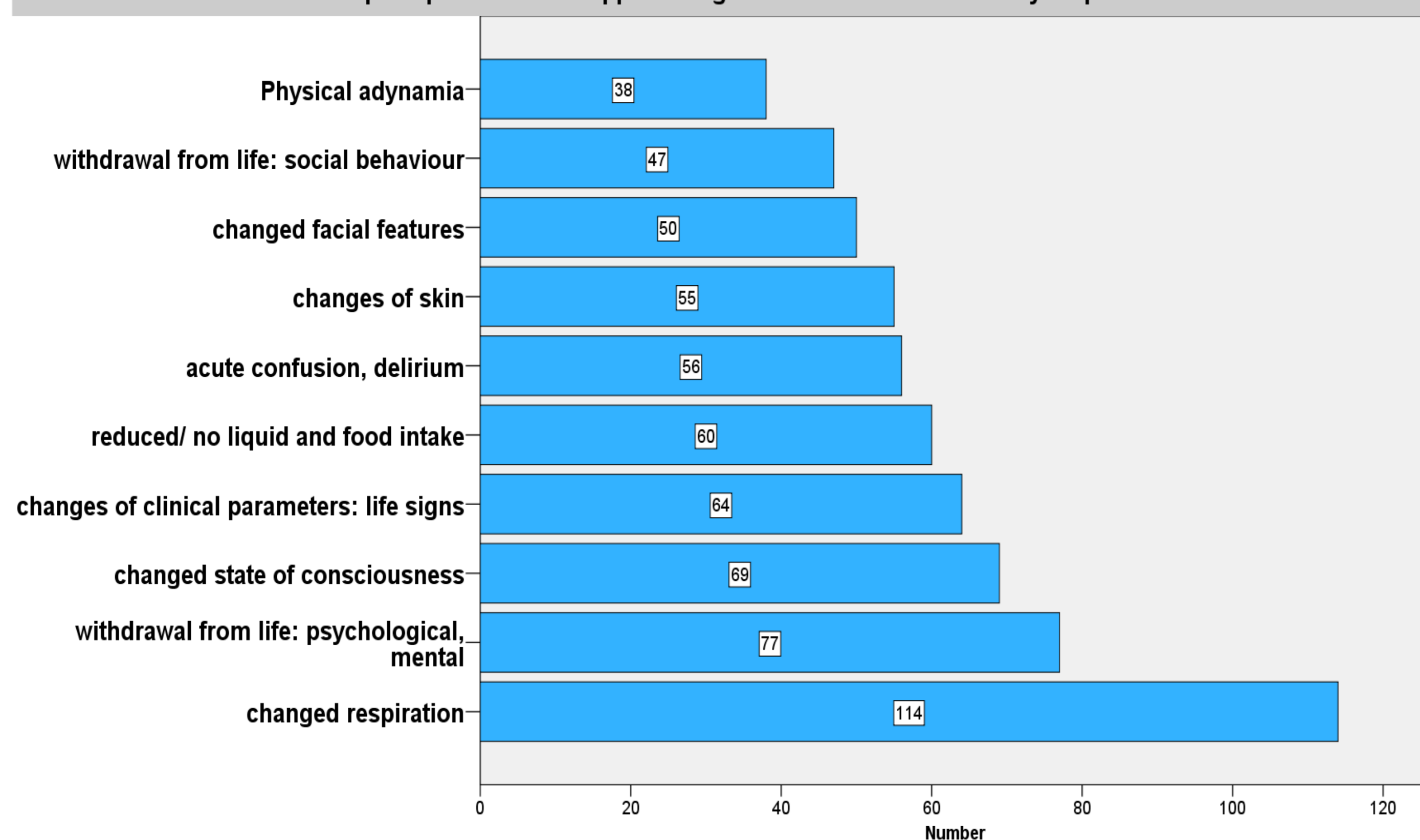
Process:



Method:

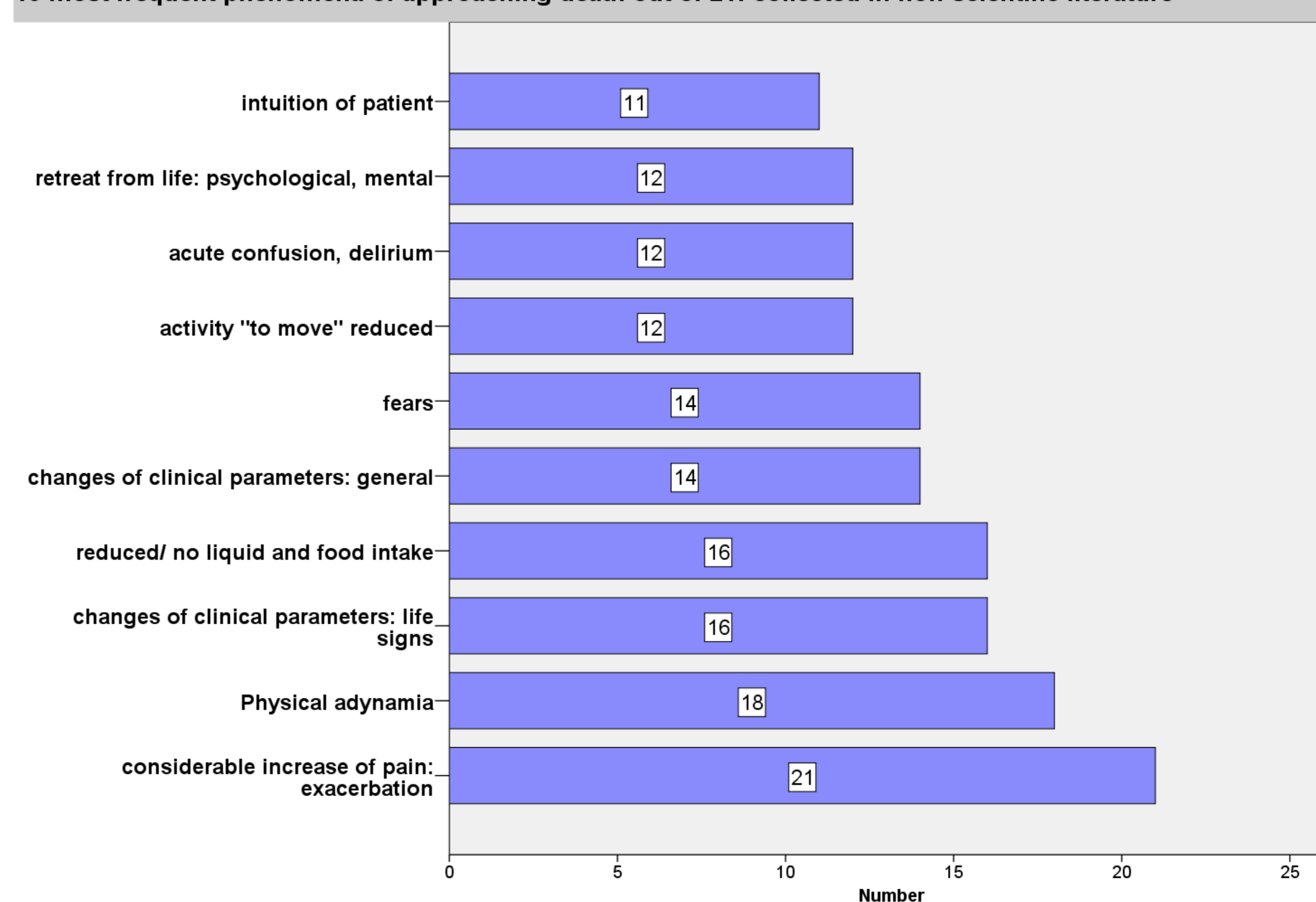


10 most frequent phenomena of approaching death out of 32: collected by Delphi method



182 participants
3 countries
1209 responses (multiple response)
32 categories (phenomena)
9 settings
9 professions of participants

10 most frequent phenomena of approaching death out of 21: collected in non-scientific literature



47 sources
21 phenomena
364 responses (multiple response)

Results:

There is a difference in the phenomena reported in the non-scientific literature compared to a Delphi among professionals. Physical symptoms predominate both searches (as change in respiration, consciousness, reduced fluid intake and other changes in clinical parameters (heart rate etc.) but "soft" factors like "adynamia", fears and "intuition" are more frequently mentioned in the non-scientific literature.

Conclusion:

- the results show a possibly important difference in phenomena predicting death and dying between the professional views and the non-scientific literature
- perspectives by lay carers are rarely systematically assessed and published
→ if the "lay" perspective is not included into "systematic" reviews at the end of life, the medicalisation of phenomena and problems might be inevitable