Decision-making in end-of-life care: in search of a registration system

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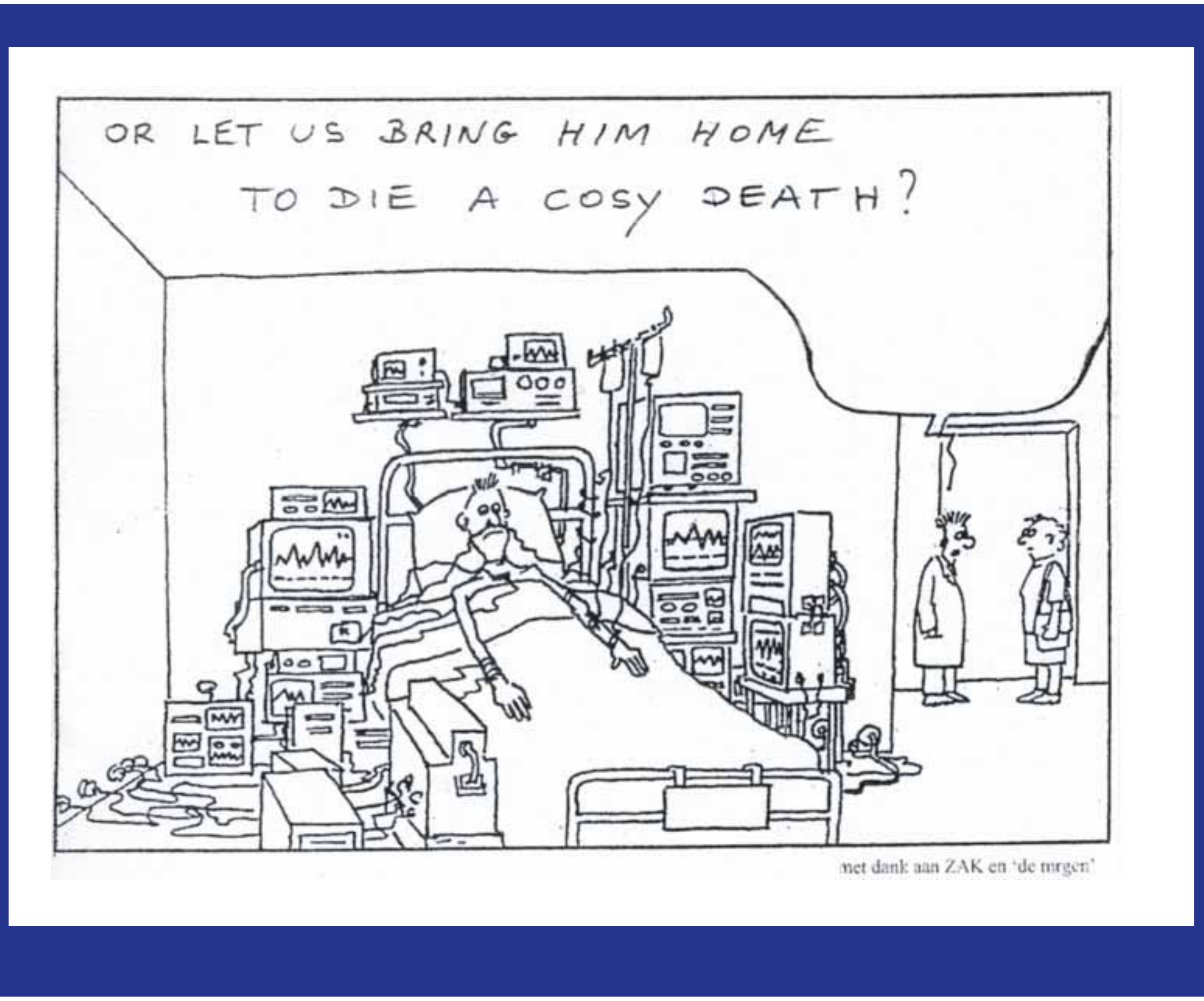
Introduction

Decision making by caregivers (CG) in end-of-life (EOL) care becomes a more persistent field of research, especially with regard to patient rights and the relation between CG and their patients. Recent publications show a trend in making the practice of CG more transparent and well-defined.
The Federal government of Belgium ordered research on the feasibility of organizing a registration system concerning EOL care. The depts. of General Practice and Primary Health Care of Ghent University and the University of Brussels were asked to conduct a pilot study aiming at following topics:

1. attitudes of CG towards EOL care
2. knowledge of the associated laws (Law on Palliative Care (PC)/Law on euthanasia/Law on patients' rights)
3. their communication skills in EOL care
4. decision-making process and medical acts in EOL care



met dank aan ZAK en 'de morgen'

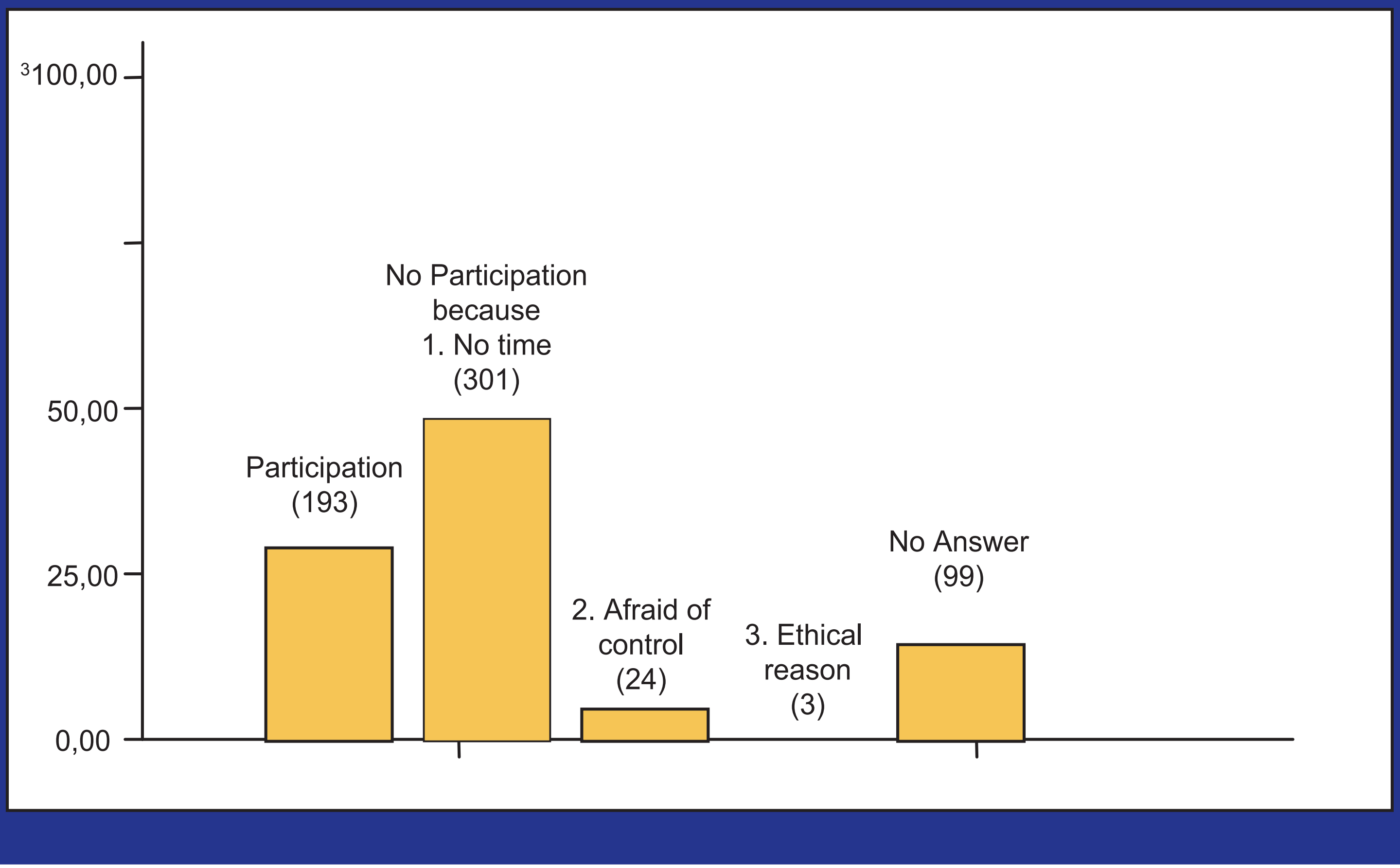
Methods

A threefold questionnaire was developed.

1. general questions about the law on patients' rights, euthanasia and PC (knowledge).
2. a retrospective survey about communication, decision making and medical acts in EOL care (attitudes, communicative aspects and decision-making processes)
3. a prospective survey on the same topics.

Three settings were selected: GPs, homes for the elderly and specialized services in hospitals.
Qualitative research was carried out in CG peer groups and interdisciplinary groups.

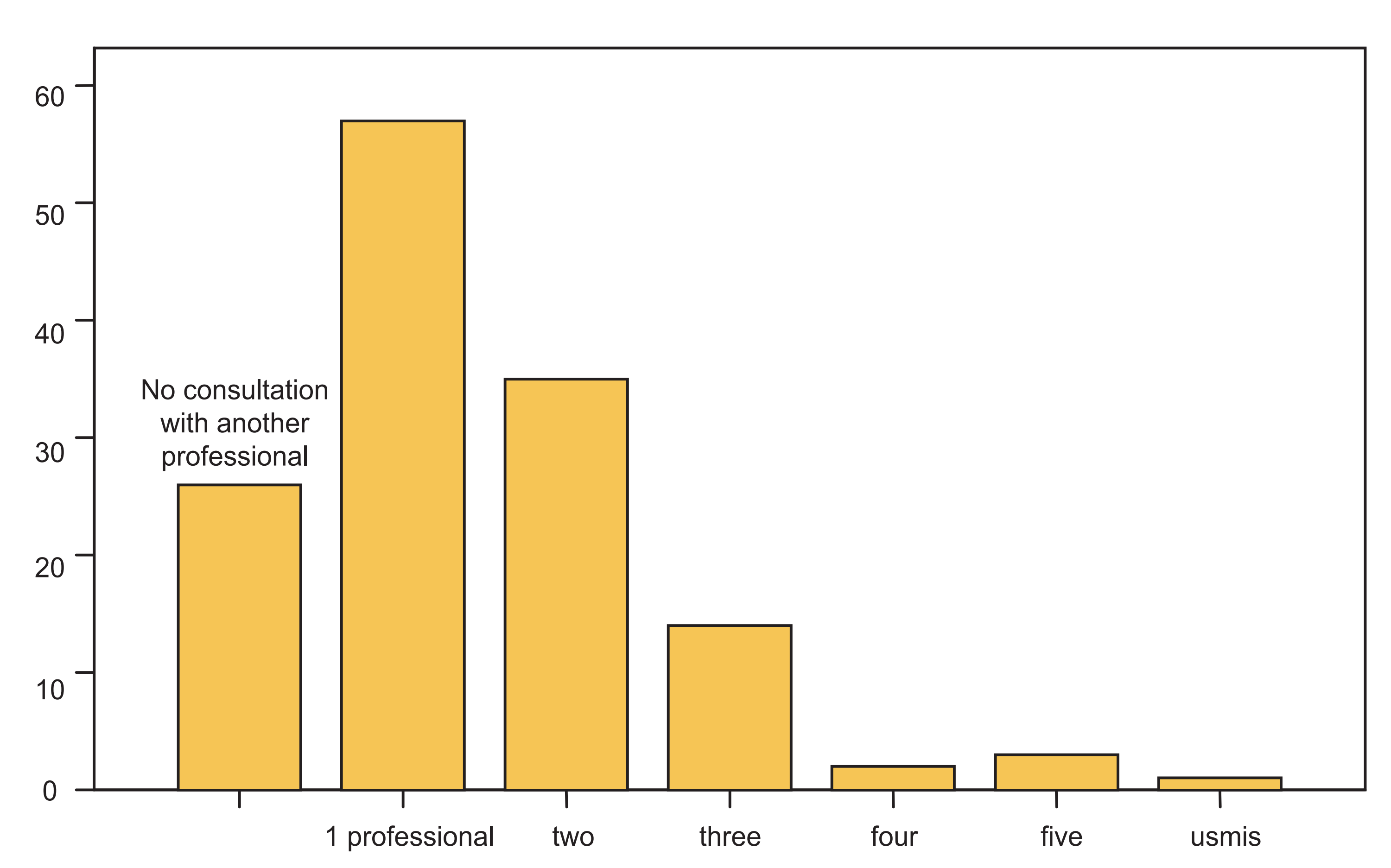
Table A
% participation in pilot study (n=620) // reasons of no participation



Preliminary results

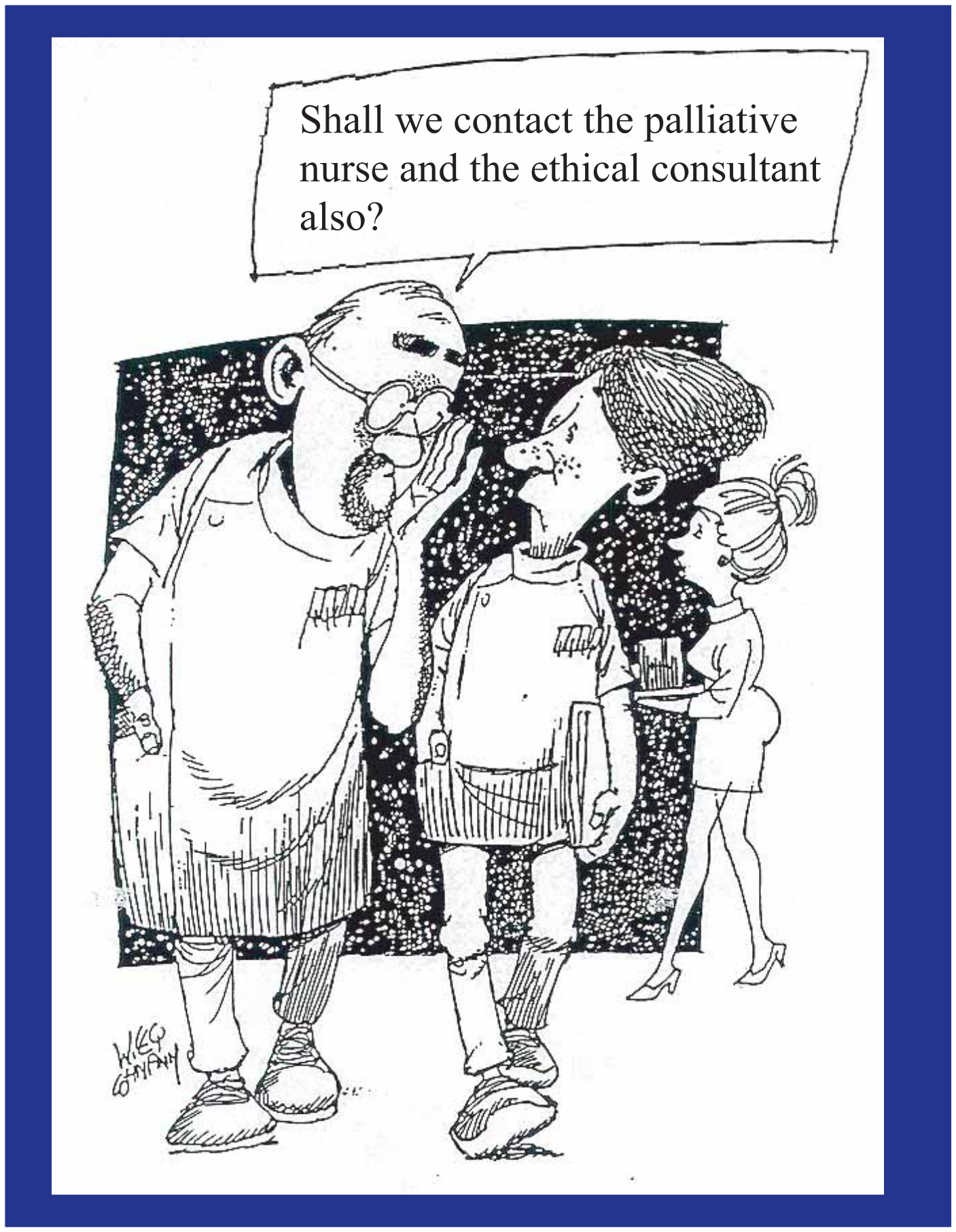
The number achieved in the pilot data collection is 193 respondents (table A).
It concerns 66% men and 34% women. 33% are specialists, 67% GPs.
Only 12 % of the MD's followed an institutionalized education in PC.
62% of the MD's offer PC to the patient. 69% agree on the fact that euthanasia should be integrated in the field of PC. 93% hold that a conceptual framework regarding EOL care is required. Less than 50% shows correct knowledge of the laws. The law on PC is least known (<30%).
More than 40% of the MD's claim the possibility to stop therapy or to give sedatives on the basis of professional autonomy instead of discussing their medical decision with the patient or relatives. There is no correlation with the will to register.
Consultation is observed in 72,5% of the retrospective cases (n=138) (table B).

Tabel B
Consultation with other professionals (138 retrospective cases)
Another colleague/palliative care giver / nurse / ethical-spiritual / other -



Tentative conclusions

- MD's are willing to participate in research and registration under certain conditions;
- a conceptual framework based on consensus is necessary for clinical practice as well as for the possibility of registration;
- further research on medical attitudes and communication patterns is necessary to give us more insight in some (disputable) medical acts;
- MD's knowledge of the law is unsatisfactory: diffusion of information via peer groups is indicated.



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