

# Paediatric End-of-Life Care Needs in Switzerland – PELICAN Study (2012 - 2015)

## Description of Current Practices (PELICAN I)

## Assessment of Parental Perspectives (PELICAN II quantitative)

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### Background

Paediatric end-of-life (EOL) care is challenging and requires a high level of professional expertise. Care services should be based on empirical evidence, be sensitive to the needs of the families concerned, take into account the heterogeneity within the medical field of paediatrics, and fit into the local health care system.

### The PELICAN Study - Methods

The general aims of the study were to provide comprehensive information and to understand the current practice of EOL care (i.e. in this study, the last 4 weeks of life prior to death) in paediatric settings in Switzerland (hospital and community care) and to explore and describe parental perspectives and the perspectives of the healthcare professionals involved.

**PELICAN I:** Data from 149 paediatric patients who died in the years 2011 or 2012 due to a cardiac, neurological or oncological condition, or during the neonatal period were collected in 13 hospitals, two long-term institutions and 10 community-based healthcare service providers throughout Switzerland. Variables collected through retrospective chart review included characteristics of patients, circumstances of death and information about several domains of EOL care.

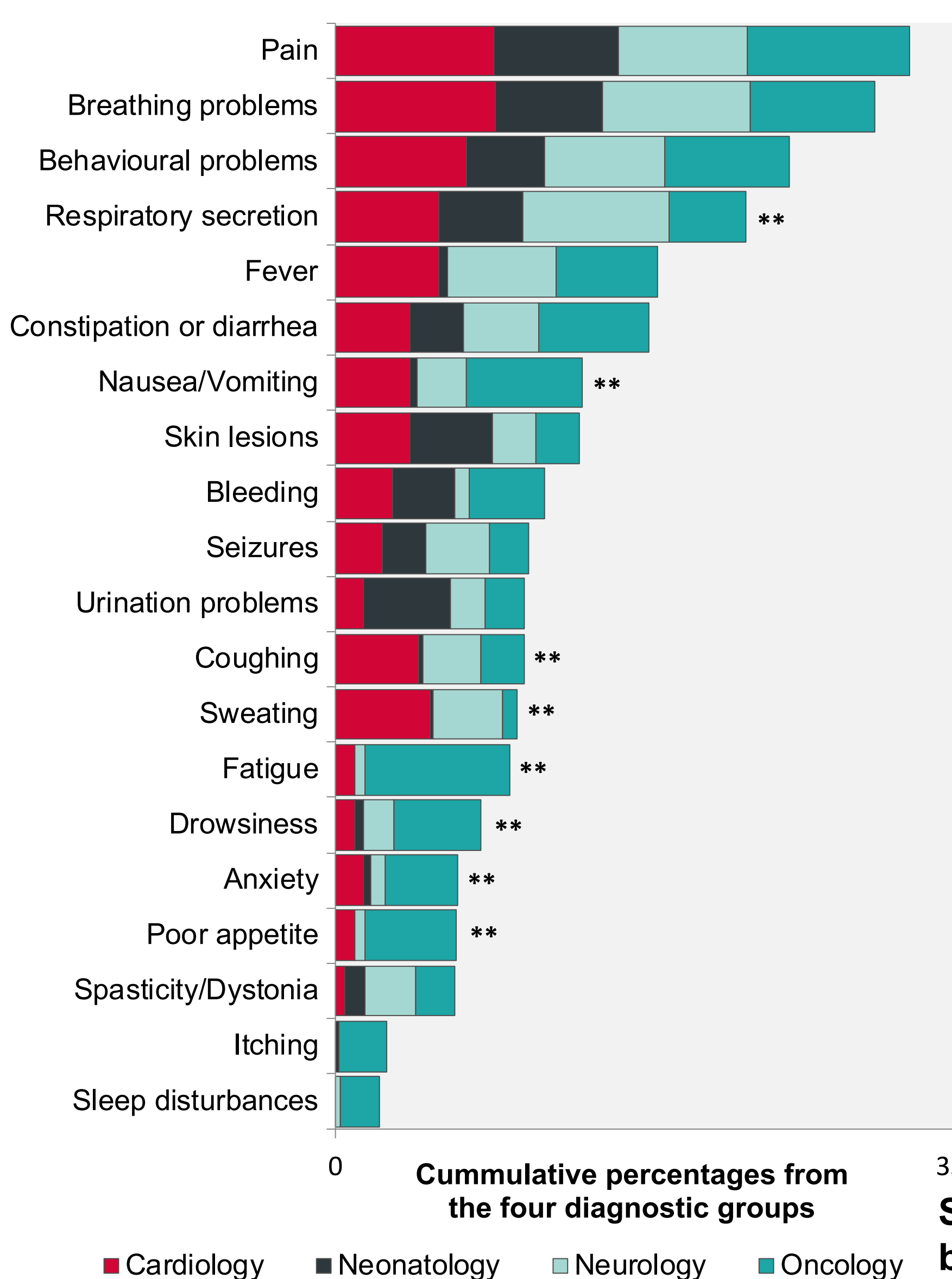
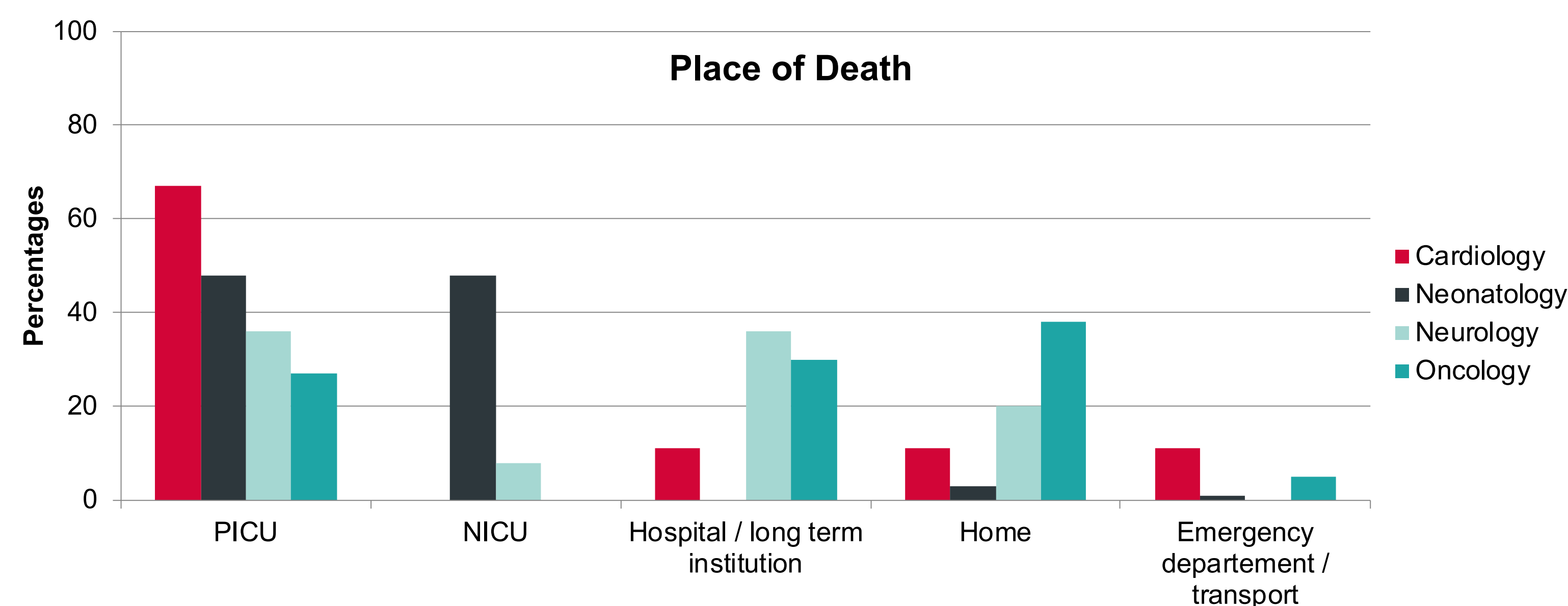
**PELICAN II:** The perspectives of 200 bereaved parents (mothers and fathers) were assessed through a questionnaire survey with a newly developed and tested instrument, the Parental PELICAN Questionnaire (PaPEQu).

Data was analysed descriptively and various regression models were applied to compare between the four diagnostic groups, including generalized estimation equation to account for the dyadic data structure with correlated data between partners (mother and father).

### Results

#### PELICAN I

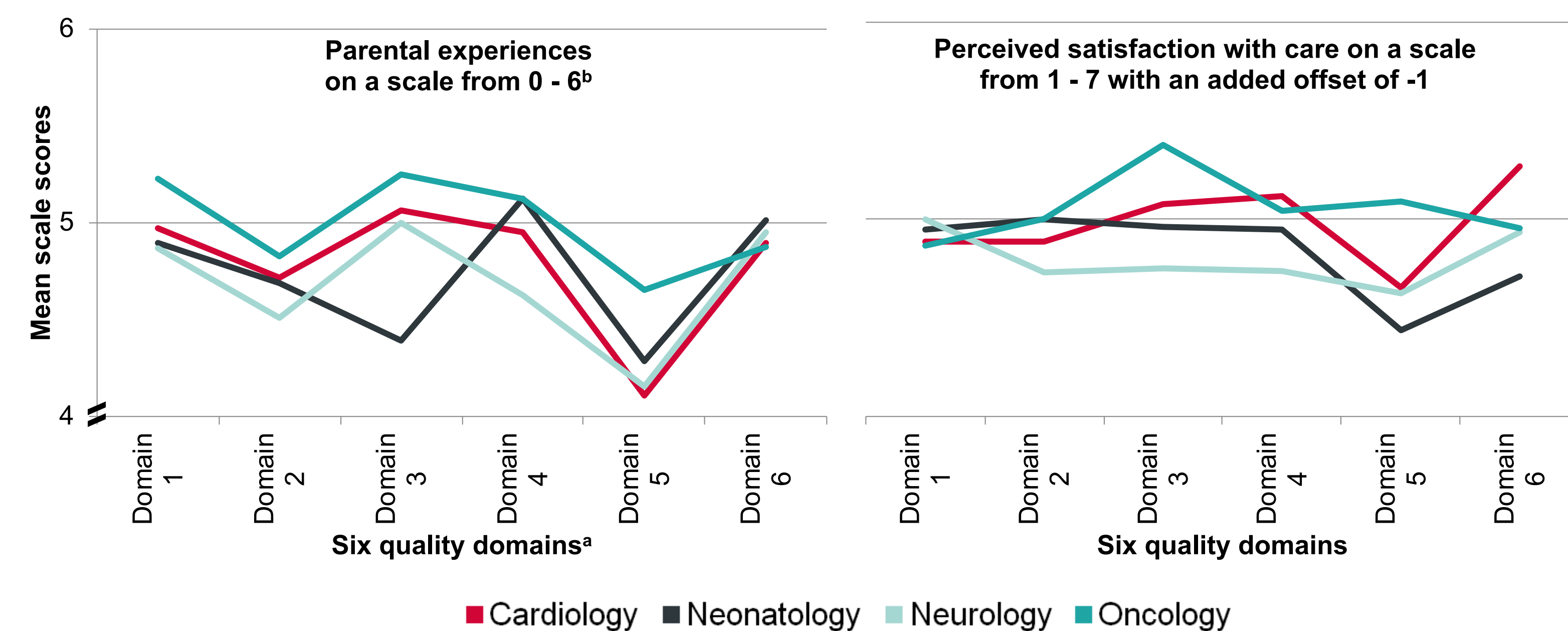
##### Place of Death



- Sixty-two percent of the patients died in intensive care units, 84% of them following the withdrawal of life-sustaining treatment.
- Reliance on invasive medical interventions was prevalent, and the use of medication was high, with a median count of 12 different drugs during the last week of life.
- Patients experienced an average number of 6.42 (SD = 3.14) symptoms. The prevalence of various types of symptoms differed significantly among the four diagnostic groups.

#### Symptom prevalence and comparison between the four diagnostic groups.

#### PELICAN II quantitative



Quality domain	Parental experiences Overall M (SD)	Perceived satisfaction with care Overall M (SD) with an offset of -1
1. Support of the family unit	4.98 (1.01)	4.96 (1.48)
2. Communication	4.68 (1.06)	4.95 (1.42)
3. Shared decision making	4.82 (1.23)	5.07 (1.42)
4. Relief of pain and other symptoms	4.99 (1.05)	4.95 (1.34)
5. Continuity and coordination of care	4.29 (1.37)	4.69 (1.55)
6. Bereavement support	4.96 (1.18)	4.89 (1.40)

<sup>a</sup>Means for the continuity of care and bereavement support domain were scaled to a range of 0 to 6.

#### Parental experiences and perceived satisfaction with care according to six quality domains

- Our findings show positive parental experiences of their child's EOL care and high perceived satisfaction with the care their child received.
- Parents of a child with cancer rated their experiences highest in most of the six quality domains and reported the highest satisfaction with care. The lowest scores were mainly reported by parents from the neurology group, with the exception of the shared decision making domain, where parents of neonates reported significantly less positive experiences.

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### Conclusions

Although positive in general, our study results suggest some areas for improvement. The integration of specialised paediatric palliative care has the potential to minimise lost opportunities to support and assist parents. Our findings provide a knowledge base for paediatric palliative care teams. As a consequence, a meaningful outcomes measure should be introduced into practice to promote quality of care and further advance research in the field.