

Brief Report

16-00319R1

Home-based palliative care for children with incurable cancer: long-term perspectives of and impact on general practitioners

Ivana M.M. van der Geest^{1,2}, Prof. Patrick J.E. Bindels³, Saskia M.F. Pluijm¹, Erna M.C. Michiels¹, Prof. Agnes van der Heide⁴, Prof. Rob Pieters², Anne-Sophie E. Darlington⁵, Marry M. van den Heuvel-Eibrink²

¹ Department of Pediatric Oncology and Hematology, Erasmus MC-Sophia Children's Hospital, 3000 CA, Rotterdam, The Netherlands

² Princess M \grave{a} xima Center for Pediatric Oncology, 3584 EA, Utrecht, The Netherlands

³ Department of General Practice, Erasmus MC, 3000 CA, Rotterdam, The Netherlands

⁴ Department of Public Health, Erasmus MC, 3000 CA, Rotterdam, The Netherlands

⁵ University of Southampton, Faculty of Health Sciences, SO17 1BJ, Southampton, United Kingdom

Corresponding author: I.M.M. van der Geest, MD, Princess M \grave{a} xima Center for Pediatric Oncology, Lundlaan 6, 3584 EA Utrecht, The Netherlands. Tel: +31-88 972 72 72. Email: i.vandergeest@erasmusmc.nl

Number of tables: 4

Number of figures: 4

Number of references: 45

Word count: 2636

ABSTRACT

Context

Although a large percentage of children with advanced-stage cancer die at home, remarkably little information is available regarding the experience of general practitioners (GPs) with respect to providing home-based palliative care to children with incurable cancer.

Objectives

To explore the perspectives of GPs who care for children with advanced-stage cancer in a home-based setting.

Methods

In this cross-sectional study, 144 GPs who provided home-based palliative care to 150 children with incurable cancer from 2001 through 2010 were invited to complete a questionnaire addressing their perspectives regarding: 1) symptom management, 2) collaboration with other health care professionals, 3) the child's death and care after death and 4) impact of having provided palliative care, scored on distress thermometer (range 0-10).

Results

A total of 112 GPs (78%) responded, and 91 GPs completed the questionnaire for 93 patients. The median interval between the child's death and completing the questionnaire was 7 years. The most prevalent symptoms reported in the patients were fatigue (67%) and pain (61%). Difficulties with communicating with (14%), coordinating with (11%), collaborating with (11%), and contacting (2%) fellow members of the multidisciplinary treatment team were rare. Hectic (7%) and shocking (5%) situations and panic (2%) around the child's death were rare. GPs reported feelings of sadness (61%) and/or powerlessness (43%) around the time of the patient's

death, and they rated their own distress level as relatively high during the terminal phase (median score: 6, range: 0-9.5). The majority of GPs (94%) reported that they ultimately came to terms with the child's death.

Conclusion

In general, GPs appear to be satisfied with the quality of home-based palliative care that they provide pediatric patients with incurable cancer. Communication among healthcare professionals is generally positive and is considered important. Finally, although the death of a pediatric patient has a profound impact on the GP, the majority of GPs eventually come to terms with the child's death.

Key words: Cancer, Children, General practice, Palliative care

Running title: Home-based pediatric palliative care

Accepted for publication: September 25, 2016.

INTRODUCTION

Approximately 25% of children diagnosed with cancer die from the disease¹. Compared to children with non-malignant diseases, children with cancer are more likely to die at home²⁻⁴. Several organizations developed guidelines to support children at the end of life, for instance the American Academy of Pediatrics and the European Association of Palliative Care^{5,6}. According to the European guideline, two healthcare models are possible in case children die at home, i.e. hospital-based care or community-based care⁶. The Dutch primary health care system is similar to several other countries in Europe, i.e. the GP functions as a primary health care professional⁷⁸. Palliative care in the Netherlands is generally embedded in general practice⁹. Home death in the Netherlands therefore implies that care is delegated to general practitioners (GPs) and community nurses, preferably supported by an experienced multidisciplinary paediatric oncology team, supporting the GP whenever necessary.

Because death of a child at home due to cancer is relatively rare, managing home-based palliative care for children with incurable cancer can be a challenge, given that children with cancer face multiple symptoms near the end of life^{10,11}. In addition, managing symptoms in children in the palliative phase is not always successful^{10,11}, and the child's suffering at the end of life is a major concern reported by parents¹². Moreover, poorly managed pain is associated with increased parental grief¹³. In addition to adequately managing the patient's symptoms, achieving effective communication, collaboration, and continuity of care among health care

professionals are recognized as determinants of providing high-quality paediatric palliative care¹⁴⁻¹⁶.

Many studies have described the key features associated with providing home-based palliative care to children with cancer from the parent's perspective, health care professionals' perspective, and/or by reviewing the child's medical information¹⁷⁻³². On the other hand, the experiences of GPs with respect to home-based palliative care in children have received relatively little attention^{27 30 31}. These few studies were small in scale (including only seven³¹ and ten GPs³⁰) or included randomly selected GPs²⁷, and emphasized the need for GPs to gain additional knowledge regarding pediatric palliative care²⁷.

Several studies reported how providing pediatric palliative care affects health care professionals³³⁻⁴¹. Thus, we hypothesized that providing home-based palliative care to a child with incurable cancer is likely a challenging task for many GPs. To test this hypothesis, we obtained the perspectives of GPs regarding their experiences associated with providing home-based palliative care to children with incurable cancer.

METHODS

Study design and participants

From 2001 through 2010, a total of 264 pediatric patients at the Erasmus MC – Sophia children's Hospital (Rotterdam, The Netherlands) died due to cancer; 150 of these patients (57%) died at home. In 2013, the 144 GPs of these 150 children were invited to complete a questionnaire asking about their experience regarding pediatric palliative care. For this study, we defined the start of the pediatric palliative care as the time at which the child and/or parents received the news that the child's disease was no longer considered curable. The GPs were sent at least one

reminder to complete the questionnaire. The study proposal was submitted to the Medical Ethics Committee of the Erasmus Medical Center (METC, Rotterdam), who ruled that the study is not under the scope of the Medical Research Involving Human Subjects Act (WMO) (number 2013-295).

Questionnaire

Because no validated questionnaire was available at the time of the study, we developed a questionnaire based on clinical experience, an extensive literature search, and discussion with professionals from the General Practice and Public Health departments. The questionnaire, which is available upon request, was reviewed by an independent GP. The questionnaire included topics such as the GP's demographic characteristics, as well as specific details regarding the child and care provided during the palliative phase, including both open-ended and closed questions regarding the following four relevant domains of pediatric palliative care: 1) symptom management; 2) collaboration with other healthcare professionals; 3) the child's death and care after death and 4) the impact of having provided palliative care. To quantify impact, a distress thermometer was used, with a score ranging from 0 (no distress) to 10 (extreme distress)⁴². GPs were instructed to reflect upon three specific time points: the pre-terminal phase, the terminal phase, and the time at which the questionnaire was completed.

Data analysis

Analyses were performed using SPSS version 21.0 (IBM Corp., Armonk, NY). Descriptive analyses were generated for all variables. Percentages were calculated based on the number of GPs who completed the specific question, including the GPs answering the question with unknown or not further specified. For the analysis of Likert scales, categories 1 and 2 were

combined to the response “disagree”, categories 4 and 5 were combined to the response “agree”, and category 3 was neutral. Non-parametric tests (the Mann–Whitney *U* test and the Kruskal–Wallis test) were used to compare the levels of distress across the GPs’ demographic characteristics and across characteristics of palliative care. Bonferroni correction was applied because of multiple comparisons ($n=36$ comparisons); a p -value ≤ 0.001 was considered statistically significant.

RESULTS

Response rate

A total of 144 GPs who provided home-based palliative care to 150 children with cancer were invited to participate, and 112 GPs (of 116 deceased children) responded (a response rate of 78%). Of the 112 GPs who responded, 91 (81%) returned a partially or fully completed questionnaire; the remaining 21 GPs of 23 deceased children declined to participate. An overview of the study is provided in Figure 1. The median interval between the child’s death and completion of the questionnaire was 7 years (range 3-12 years).

Characteristics of the participating GPs

The demographic characteristics of the participating GPs are summarized in Table 1. The majority of GPs stated that they remembered the child ($n=85$, 92%), and/or the palliative phase very well ($n=72$, 80%). Two-thirds of the GPs (67%) stated that this was the first time in their career that they cared for a child during the palliative phase. Collaboration with other health care professionals was in the majority of cases remembered ($n=51$, 56%) or vaguely remembered ($n=30$, 33%). Approximately one-third of the GPs ($n=29$, 31%) were present at the time of the

child's death. With respect to the duration of the palliative phase, according to GPs, 7% of cases (n=6) lasted less than one week, 33% of cases (n=30) lasted 1-4 weeks, 28% of cases (n=26) lasted 5-10 weeks, and 28% of cases (n=26) lasted longer than 10 weeks.

Symptom management

The symptoms and how well the GPs managed those symptoms are summarized in Figure 2. The GPs assessed the severity of the child's symptoms using a variety of approaches, including discussion with the child's parent(s) (n=81, 91%), communicating directly with the child (n=49, 55%), performing a medical examination of the child (n=49, 55%), and/or reviewing the nurses' notes (n=21, 24%). A total of 29 GPs (33%) reported that they did not receive sufficient information from the hospital regarding possible symptoms and potential difficulties during the palliative phase, and the majority of these GPs stated that they would have appreciated receiving such information.

Figure 3 summarizes the palliative treatments administered at home. In two cases, the GPs reported that they could not provide the necessary treatment in time; these treatments included placement of a urinary bladder catheter and midazolam suppositories. Lastly, the GPs reported that practical problems associated with administering pain medication in the patient's home were rare (Figure 4).

Collaboration between the GP and other health-care professionals

The perspectives of the GPs with respect to communicating with, coordinating with, collaborating with, and the accessibility of other healthcare professionals are summarized in Table 2. The GP was first contacted by the hospital's pediatric oncology department either

shortly after the child was first diagnosed (n=24, 26%), during the child's treatment (n=22, 24%), or when it became clear that the disease had progressed to the terminal (incurable) stage (n=31, 34%). Shortly after the family was informed that curative treatment was no longer possible, 43 GPs (47%) considered only themselves in charge of the day-to-day palliative care, and this number increased to 72 GPs (78%) just prior to the child's death.

With respect to collaborating with other healthcare providers, 52 GPs collaborated with pediatric oncologists (57%), 42 with community nurses (46%), 34 with colleagues (i.e., fellow GPs; 37%), 25 with secondary care pediatricians (27%), 13 with members of a pain-management team (14%), 11 with secondary care nurses (12%), 9 with tertiary care nurses (10%), 5 with social workers (5%), 2 with pediatric psychologists (2%), 1 with a child life specialist (1%), and 1 with a chaplain (1%). Note that some GPs collaborated with more than one additional healthcare provider. Interestingly, 25 GPs (27%) reported that involving a pediatric psychosocial expert would have been a positive addition to the multidisciplinary care team.

Seventeen GPs (19%) had the direct mobile phone number for a pediatric oncologist. Nearly all of these GPs (n=15, 94%) indicated that they appreciated having this number, and 69% actually used it. Among the 52 GPs who did not have direct telephone access to a pediatric oncologist, the majority (n=28, 74%) indicated that they would have appreciated it. Nearly 70% of the GPs provided the parents with their direct mobile phone number, and 51 of these parents (80%) used it.

Experiences of the GPs around the time of the child's death, and thereafter

The time at which the child died was best described by 77 GPs (90%) as 'expected' and/or by 75 GPs (96%) as 'well-prepared'. The atmosphere surrounding the child's death was often

described as a rather positive experience by the GPs, who used the terms ‘calm’ (n=54, 62%), ‘intimate’ (n=34, 39%) and/or ‘appropriate’ (n=24, 28%). Terms that were used less frequently by the GPs included ‘beautiful’ (n=10, 12%), ‘restless’ (n=10, 12%), ‘hectic’ (n=6, 7%), ‘shocking’ (n=4, 5%) and ‘panic’ (n=2, 2%).

After the child died, 12 (14%) and 68 (78%) GPs had one or more discussions, respectively, with the child’s parents to reflect upon the palliative phase. Thirty-five parents (40%) and 21 siblings (24%) were referred by the GP for further care, which was often psychological in nature. In 28% of cases (n=25), the GP evaluated the palliative care with the collaborating health-care professionals. Among the 63 GPs (72%) who did not have such an evaluation, 18 GPs indicated that they would have appreciated such an opportunity.

Impact of providing paediatric palliative care on the GPs

The impact of providing palliative care on the GPs is summarized in Table 3. The median score for the distress thermometer during the pre-terminal phase, during the terminal phase, and at the time the questionnaire was completed was 4 (range: 0-8), 6 (range: 0-9.5), and 0 (range: 0-8), respectively. The GPs reported that, among others, they received support for coming to terms with the patient’s death from his/her own family members (n=61, 70%), fellow GPs (n=40, 46%), and/or friends (n=15, 17%). A few factors were associated with increased levels of distress in the GPs during the terminal phase (Table 4). After Bonferroni correction, none of these associations were statistically significant.

DISCUSSION

In general, the GPs who participated in our study reported being satisfied with the quality of palliative care provided to their pediatric cancer patients. Communication between the GP and other healthcare professionals was experienced as positive and was considered important by the GPs. Although the death of the child generally had a strong impact on the GP, the majority of GPs eventually came to terms with the child's death. Obtaining the perspective of GPs with respect to providing home-based palliative care to children with incurable cancer is highly relevant, as the majority of children with incurable cancer die at home²⁻⁴. Because the role of the GP in providing home-based care differs among countries, translating our findings into clinical practice will depend on the country of interest.

Our results show that from the GP's perspective, children who receive home-based palliative care frequently experience pain and/or fatigue, while relatively less often, the GPs remembered psychological symptoms in the child, including feelings of fear and/or anger. This finding is consistent with a previous study reporting that from the parents' perspective, most healthcare professionals tend to notice physical symptoms more often than they notice psychological symptoms⁴³. The majority of GPs in our study reported that their assessment of the child's symptoms was based primarily on information obtained from the parents. GPs tend to rely more upon their clinical experience and/or communication with family members than on validated instruments when assessing the child's symptoms in a home-based setting. Practical problems with respect to prescribing pain medications occurred occasionally, and situations in which treatment was not available in a timely manner were rare. Nevertheless, a large subset of GPs expressed their desire to receive more structured information from the pediatric oncology department regarding the management of their patients' pain and other symptoms.

It is interesting to note that the participating GPs were highly satisfied with their own performance, which may indicate that not all physicians are able to critically reflect on their own performance, especially in a sensitive area such as end-of-life care. A systematic review of the accuracy of physicians' self-assessment indeed demonstrated their limited ability to self-assess⁴⁴, which should be taken into consideration when interpreting our findings as this may result in underestimation of the child's level of suffering. Moreover, it is interesting that GPs reported that they were highly satisfied with symptom management, while they also preferred to have more information on how to manage the child's symptoms. This may reflect the need of GPs for education or expert advice, which is in line with existing literature^{27 39 41}.

Our study provides evidence that GPs report experiencing physical and/or psychological symptoms surrounding the death of a pediatric patient with incurable cancer. This finding is consistent with previous studies in health care professionals³³⁻⁴¹. Liben and colleagues previously reported that healthcare professionals often rely upon colleagues for support more than their family and friends⁴⁵, whereas we found that GPs generally receive support from own family members and—to a lesser extent—their colleagues. One possible explanation for this difference is that the GPs might have less frequent daily contact with their colleagues. The majority of participating GPs did not indicate that they would have preferred to receive professional help with respect to coming to terms with the child's death, nor did they prefer the opportunity to speak further with their colleagues regarding the patient's death. These findings seem to be in contrast with the relatively high burden that was reported among GPs. However, the majority of GPs had come to terms with the child's death by the time they completed the questionnaire.

This study has several possible limitations that warrant discussion. First, when completing the questionnaire, the GPs had to rely on their memory of specific details regarding the palliative care provided and their own emotional feelings at the time of the child's death; in some cases, several years had passed between the child's death and completion of the questionnaire. Despite this seemingly long interval, however, impactful events such as the death of a pediatric patient with a prolonged illness are often remembered well by general practitioners; therefore, recall bias may not have been a strong confounding factor. In addition, no information was obtained from the other healthcare professionals who were involved in the child's palliative care.

Based on our findings, we recommend that evidence-based guidelines be developed in order to better support GPs who care for children with advanced-stage cancer. For example, such guidelines should include information regarding the frequency of symptoms experienced by patients and the management of those symptoms. Knowing that clinicians often express a need for more education in knowledge on paediatric palliative care, this is in line with developing future guidelines.

Acknowledgments

The authors have declared no conflicts of interest.

Funding

No funding.

References

1. Gatta G, Botta L, Rossi S, et al. Childhood cancer survival in Europe 1999-2007: results of EUROCARE-5--a population-based study. *Lancet Oncol* 2014;**15**(1):35-47.
2. Chang E, MacLeod R, Drake R. Characteristics influencing location of death for children with life-limiting illness. *Arch Dis Child* 2013;**98**(6):419-24.
3. Feudtner C, Feinstein JA, Satchell M, et al. Shifting place of death among children with complex chronic conditions in the United States, 1989-2003. *JAMA* 2007;**297**(24):2725-32.
4. Siden H, Miller M, Straatman L, et al. A report on location of death in paediatric palliative care between home, hospice and hospital. *Palliat Med* 2008;**22**(7):831-4.
5. American Academy of Pediatrics. Committee on Bioethics and Committee on Hospital Care. Palliative care for children. *Pediatrics* 2000;**106**(2 Pt 1):351-7.
6. European Association for Palliative Care (EAPC). Palliative care for infants, children and young people: The facts. 2009. <http://www.eapcnet.eu/LinkClick.aspx?fileticket=DeiV2yhtOZA%3D>.
7. van der Zee J, Kroneman M, Boerma W. 'De Nederlandse huisarts in Europees perspectief'- The Dutch GP in a European context. *Huisarts Wet* 2004;**47**(6):226-73.
8. Allen J, Gay B, Crebolder H, et al. The European definition of general practice/family medicine. *Wonca Europe*. 2011.
9. Franke AL. Palliative care for terminally ill patients in the Netherlands: Dutch government policy. Den Haag; Ministerie van Volksgezondheid, Welzijn en Sport. 2003.
10. Wolfe J, Grier HE, Klar N, et al. Symptoms and suffering at the end of life in children with cancer. *N Engl J Med* 2000;**342**(5):326-33.
11. Wolfe J, Hammel JF, Edwards KE, et al. Easing of suffering in children with cancer at the end of life: is care changing? *J Clin Oncol* 2008;**26**(10):1717-23.
12. Hinds PS, Schum L, Baker JN, et al. Key factors affecting dying children and their families. *J Palliat Med* 2005;**8 Suppl 1**:S70-8.
13. van der Geest IM, Darlington AS, Streng IC, et al. Parents' experiences of pediatric palliative care and the impact on long-term parental grief. *J Pain Symptom Manage* 2014;**47**(6):1043-53.
14. Gilmer MJ, Foster TL, Bell CJ, et al. Parental perceptions of care of children at end of life. *Am J Hosp Palliat Care* 2013;**30**(1):53-8.
15. Contro N, Larson J, Scofield S, et al. Family perspectives on the quality of pediatric palliative care. *Arch Pediatr Adolesc Med* 2002;**156**(1):14-9.
16. Heller KS, Solomon MZ, Initiative for Pediatric Palliative Care Investigator T. Continuity of care and caring: what matters to parents of children with life-threatening conditions. *J Pediatr Nurs* 2005;**20**(5):335-46.
17. Schmidt P, Otto M, Hechler T, et al. Did increased availability of pediatric palliative care lead to improved palliative care outcomes in children with cancer? *J Palliat Med* 2013;**16**(9):1034-9.

18. Collins JJ, Stevens MM, Cousens P. Home care for the dying child. A parent's perception. *Aust Fam Physician* 1998;**27**(7):610-4.
19. Vollenbroich R, Duroux A, Grasser M, et al. Effectiveness of a pediatric palliative home care team as experienced by parents and health care professionals. *J Palliat Med* 2012;**15**(3):294-300.
20. Surkan PJ, Dickman PW, Steineck G, et al. Home care of a child dying of a malignancy and parental awareness of a child's impending death. *Palliat Med* 2006;**20**(3):161-9.
21. Friedrichsdorf SJ, Postier A, Dreyfus J, et al. Improved quality of life at end of life related to home-based palliative care in children with cancer. *J Palliat Med* 2015;**18**(2):143-50.
22. Groh G, Borasio GD, Nickolay C, et al. Specialized pediatric palliative home care: a prospective evaluation. *J Palliat Med* 2013;**16**(12):1588-94.
23. Sirkia K, Saarinen UM, Ahlgren B, et al. Terminal care of the child with cancer at home. *Acta Paediatr* 1997;**86**(10):1125-30.
24. Niswander LM, Cromwell P, Chirico J, et al. End-of-life care for children enrolled in a community-based pediatric palliative care program. *J Palliat Med* 2014;**17**(5):589-91.
25. Arland LC, Hendricks-Ferguson VL, Pearson J, et al. Development of an in-home standardized end-of-life treatment program for pediatric patients dying of brain tumors. *J Spec Pediatr Nurs* 2013;**18**(2):144-57.
26. Kopecky EA, Jacobson S, Joshi P, et al. Review of a home-based palliative care program for children with malignant and non-malignant diseases. *J Palliat Care* 1997;**13**(4):28-33.
27. Straatman L, Miller T. Paediatric palliative care: a survey of paediatricians and family practitioners. *BMJ Support Palliat Care* 2013;**3**(3):366-71.
28. Junger S, Vedder AE, Milde S, et al. Paediatric palliative home care by general paediatricians: a multimethod study on perceived barriers and incentives. *BMC Palliat Care* 2010;**9**:11.
29. Friedrichsdorf SJ, Menke A, Brun S, et al. Status quo of palliative care in pediatric oncology-a nationwide survey in Germany. *J Pain Symptom Manage* 2005;**29**(2):156-64.
30. Neilson SJ, Kai J, Macarthur C, et al. Caring for children dying from cancer at home: a qualitative study of the experience of primary care practitioners. *Fam Pract* 2011;**28**(5):545-53.
31. Spencer L, Battye L. Palliative care in the community for children with cancer in South East England. *Eur J Oncol Nurs* 2001;**5**(3):190-7.
32. Beringer AJ, Eaton NM, Jones GL. Providing a children's palliative care service in the community through fixed-term grants: the staff perspective. *Child Care Health Dev* 2007;**33**(5):619-24.
33. Papadatou D, Bellali T, Papazoglou I, et al. Greek nurse and physician grief as a result of caring for children dying of cancer. *Pediatr Nurs* 2002;**28**(4):345-53.
34. Baughcum AE, Gerhardt CA, Young-Saleme T, et al. Evaluation of a pediatric palliative care educational workshop for oncology fellows. *Pediatr Blood Cancer* 2007;**49**(2):154-9.
35. Davies B, Clarke D, Connaughty S, et al. Caring for dying children: nurses' experiences. *Pediatr Nurs* 1996;**22**(6):500-7.
36. Clarke-Steffen L. The meaning of peak and nadir experiences of pediatric oncology nurses: secondary analysis. *J Pediatr Oncol Nurs* 1998;**15**(1):25-33.
37. Papadatou D, Martinson IM, Chung PM. Caring for dying children: a comparative study of nurses' experiences in Greece and Hong Kong. *Cancer Nurs* 2001;**24**(5):402-12.
38. Hinds PS, Puckett P, Donohoe M, et al. The impact of a grief workshop for pediatric oncology nurses on their grief and perceived stress. *J Pediatr Nurs* 1994;**9**(6):388-97.
39. Khaneja S, Milrod B. Educational needs among pediatricians regarding caring for terminally ill children. *Arch Pediatr Adolesc Med* 1998;**152**(9):909-14.
40. Kaplan LJ. Toward a model of caregiver grief: Nurses' experiences of treating dying children. *Omega-J Death Dying* 2000;**41**(3):187-206.

41. Contro NA, Larson J, Scofield S, et al. Hospital staff and family perspectives regarding quality of pediatric palliative care. *Pediatrics* 2004;**114**(5):1248-52.
42. Tuinman MA, Gazendam-Donofrio SM, Hoekstra-Weebers JE. Screening and referral for psychosocial distress in oncologic practice: use of the Distress Thermometer. *Cancer* 2008;**113**(4):870-8.
43. Theunissen JM, Hoogerbrugge PM, van Achterberg T, et al. Symptoms in the palliative phase of children with cancer. *Pediatr Blood Cancer* 2007;**49**(2):160-5.
44. Davis DA, Mazmanian PE, Fordis M, et al. Accuracy of physician self-assessment compared with observed measures of competence: a systematic review. *JAMA* 2006;**296**(9):1094-102.
45. Liben S, Papadatou D, Wolfe J. Paediatric palliative care: challenges and emerging ideas. *Lancet* 2008;**371**(9615):852-64.

Table 1. Characteristics of GPs (n=91)

| Characteristics | |
|---|------------|
| Gender, n (%) | |
| Male | 67 (74%) |
| Female | 24 (26%) |
| Age at time of the study, median [range] | 56 [35-71] |
| Age at palliative phase, median [range]* | 48 [32-65] |
| Marital status, n (%) | |
| Married/living together | 84 (93%) |
| Divorced | 3 (3%) |
| Single | 2 (2%) |
| Not stated | 2 (2%) |
| Having children, n (%) | |
| Yes | 77 (85%) |
| No | 11 (12%) |
| Not stated | 3 (3%) |
| Number of children, median [range] | 3 [1-5] |
| Religion, n (%) | |
| No religion | 45 (50%) |
| Protestant | 22 (24%) |
| Roman Catholic | 18 (20%) |
| Others | 5 (5%) |

| | |
|---|-----------|
| Not stated | 1 (1%) |
| Importance religion, n (%) | |
| Very important | 14 (15%) |
| Somewhat important | 28 (31%) |
| Little important | 28 (31%) |
| Not important | 19 (21%) |
| Not stated | 2 (2%) |
| Currently working as GP, n (%) | |
| Yes | 76 (84%) |
| No | 15 (16%) |
| Years of experience as GP at time of the study, median [range] | 23 [5-39] |
| Years of experience as GP at palliative phase, median [range]* | 15 [0-32] |
| Previous education about paediatric palliative care, n (%) | |
| Yes | 2 (2%) |
| No | 86 (95%) |
| N.A. (no specific GP education) | 3 (3%) |

*Characteristics are presented as number and frequency or median and range. *=age at palliative phase and years of experience as GP at palliative phase were calculated for all children (n=93).*

Table 2. General practitioners' satisfaction with symptom management, communication, coordination, collaboration and accessibility

| | Difficulties experienced by GPs | (Some- what) Disagree | Neutral | (Some- what) Agree | N.A. |
|--|--|--------------------------------------|----------------|-----------------------------------|-------------|
| Symptom management | - | | | | |
| <i>'I was satisfied with the extent to which the child's physical symptoms were controlled'</i> | | 12 (13%) | 9 (10%) | 62 (70%) | 6 (7%) |
| <i>'I was satisfied with the extent to which the child's psychological symptoms were controlled'</i> | | 11 (12%) | 17 (19%) | 49 (55%) | 12 (14%) |
| Communication | N=13 (14%) | | | | |
| <i>'I was satisfied with the content of the handover of medical care from the tertiary line'</i> | | 10(11.5%) | 12 (14%) | 55 (63%) | 10(11.5%) |
| <i>'I would have appreciated more communication with the third line before the child's death'</i> | | 31 (36%) | 16 (18%) | 32 (37%) | 8 (9%) |
| <i>'I would have appreciated more communication with the third line after the child's death'</i> | | 42(49.5%) | 19 (22%) | 16 (19%) | 8(9.5%) |
| Coordination | N=10 (11%) | | | | |
| <i>'It was clear to me what my role was during the palliative phase'</i> | | 13 (15%) | 13 (15%) | 60 (68%) | 2 (2%) |
| <i>'I would have appreciated a clearer description of my role during the palliative phase'</i> | | 36 (42%) | 17 (20%) | 28 (32%) | 5 (6%) |
| <i>'I was satisfied with the timing of the handover of medical care from the tertiary line'</i> | | 10 (11%) | 12 (14%) | 54 (62%) | 11 (13%) |
| <i>'I was satisfied with the role of the third line in terms of coordination of medical care'</i> | | 13 (15%) | 22 (25%) | 41 (47%) | 11 (13%) |

| | | | | | |
|--|------------|----------|----------|----------|----------|
| <i>'I was satisfied with how I coordinated medical care in the last days before the child's death'</i> | | 4 (5%) | 10 (11%) | 68 (77%) | 6 (7%) |
| Collaboration | N=10 (11%) | | | | |
| <i>'Collaboration with the primary care went well'</i> | | 1 (1%) | 8 (9%) | 66 (75%) | 13 (15%) |
| <i>'Collaboration with secondary care went well'</i> | | 5 (6%) | 12 (14%) | 59 (68%) | 10 (12%) |
| <i>'Collaboration with tertiary care went well'</i> | | 8 (9%) | 13 (15%) | 53 (62%) | 12 (14%) |
| <i>'I felt supported by the tertiary line in relation to the care of the child'</i> | | 13 (15%) | 14 (16%) | 50 (57%) | 11 (12%) |
| Accessibility | N=2 (2%) | | | | |
| <i>'I was satisfied with the accessibility of staff of the third line before the child's death'</i> | | 3 (3%) | 19 (22%) | 54 (61%) | 12 (14%) |
| <i>'I was satisfied with the accessibility of staff of the third line after the child's death'</i> | | 1 (1%) | 24 (28%) | 23 (27%) | 38 (44%) |

General practitioners rated agreement on a five-point Likert scale (1 and 2=(somewhat) disagree; 3=neutral; 4 and 5=(somewhat) agree). Results are presented as numbers and percentages. N.A. = not applicable or not known.

Table 3. Physical and emotional impact

| Statements | (Some- what) Disagree | Neutral | (Some- what) Agree | N.A. |
|--|--------------------------------------|----------------|-----------------------------------|-------------|
| <i>'The impact of the child's death was bigger than the death of an adult in my practice'</i> | 5 (6%) | 3 (3%) | 78 (91%) | - |
| <i>'I experienced insomnia around the time of death'</i> | 53 (61%) | 7 (8%) | 23 (26%) | 4 (5%) |
| <i>'I felt tired around the time of death'</i> | 43 (49%) | 9 (10%) | 32 (37%) | 3 (4%) |
| <i>'I experienced reduced appetite around the child's death'</i> | 68 (78%) | 12 (14%) | 3 (3%) | 4 (5%) |
| <i>'I felt anxious around the child's death'</i> | 69 (79%) | 7 (8%) | 7 (8%) | 4 (5%) |
| <i>'I was sad around the child's death'</i> | 27 (31%) | 6 (7%) | 52 (61%) | 1 (1%) |
| <i>'I felt powerless because the situation around the child's death'</i> | 35 (41%) | 13 (15%) | 37 (43%) | 1 (1%) |
| <i>'I spoke extensively with colleagues about the child's death'</i> | 38 (44%) | 12 (14%) | 36 (41%) | 1 (1%) |
| <i>'I would have like more opportunity to speak with colleagues about the child's death'</i> | 56 (64%) | 19 (22%) | 11 (13%) | 1 (1%) |
| <i>'I would have like professional help with coming to terms with the child's death'</i> | 70 (81%) | 7 (8%) | 8 (9%) | 2 (2%) |
| <i>'I feel positive about the circumstances surrounding the child's death, despite it being difficult'</i> | 6 (7%) | 6 (7%) | 74 (86%) | - |
| <i>'I have been able to come to terms with the child's death'</i> | - | 3 (4%) | 82 (94%) | 2 (2%) |

General practitioners rated agreement on a five-point Likert scale (1 and 2=(somewhat) disagree; 3=neutral; 4 and 5=(somewhat) agree). Results are presented as numbers and percentages. N.A. = not applicable or not known.

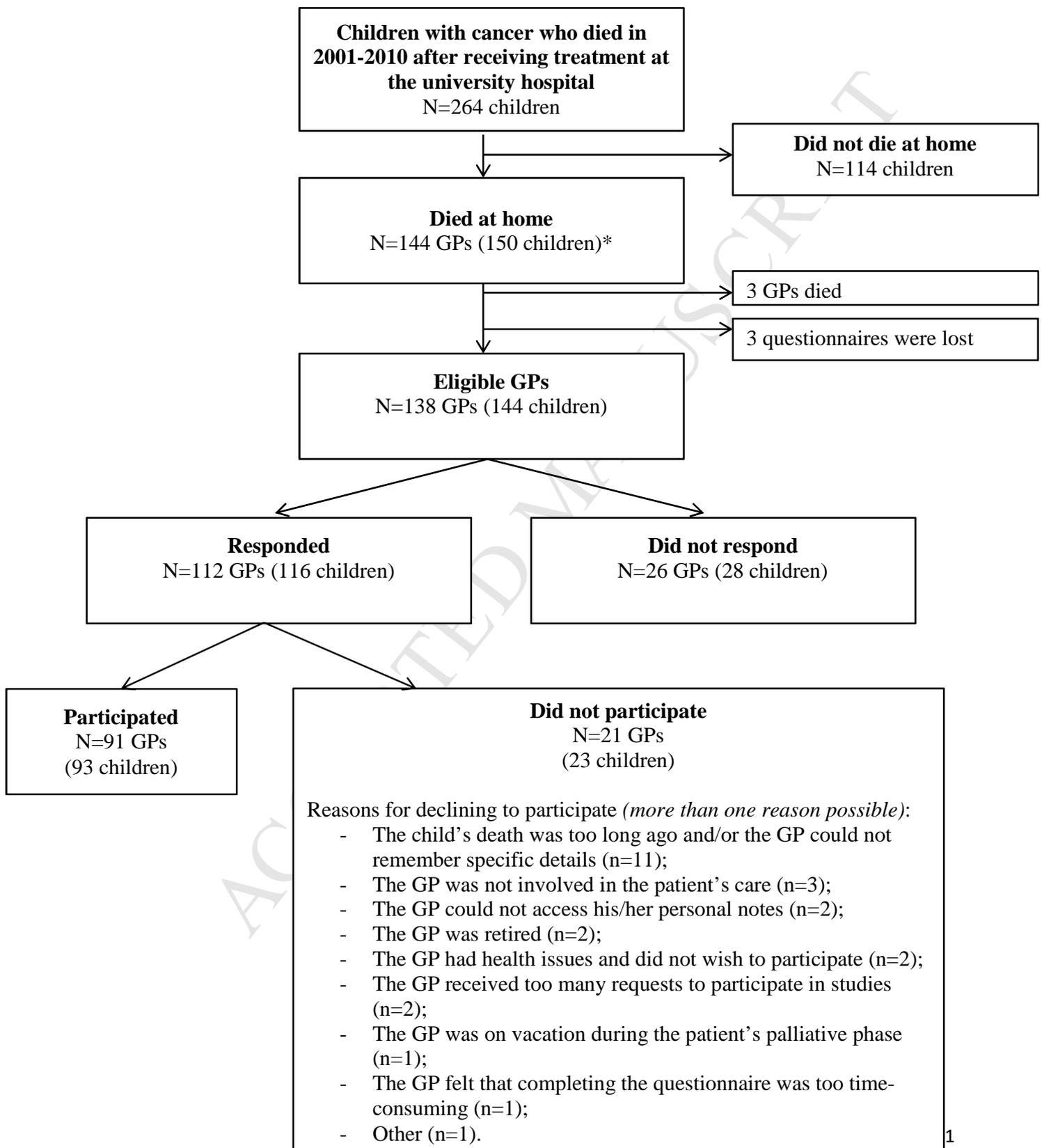
ACCEPTED MANUSCRIPT

Table 4. Impact of paediatric palliative care on GPs during the terminal phase

| | Distress Thermometer (Terminal phase) Median [range] | P-value |
|------------------------------|---|----------------|
| Gender | | 0.05 |
| Male | 5 [0-9] | |
| Female | 6 [0-9.5] | |
| Marital status | | 0.73 |
| Living together or married | 6 [0-9] | |
| Single, divorced or widower | 3 [0-9.5] | |
| Having children | | 0.63 |
| Yes; No | 6 [0-9]; 6 [0-9] | |
| First time child died | | 0.06 |
| Yes; No | 6 [0-9.5]; 4 [0-8.5] | |
| Present at death | | 0.10 |
| Yes; No | 4 [0-9.5]; 6 [0-9] | |
| Importance of faith | | 0.63 |
| Very important | 4 [1-9] | |
| Somewhat important | 5.5 [0-9.5] | |
| Little important | 5.5 [0.5-9] | |
| Not important | 7 [0-8] | |

| | | |
|---|------------------------|------|
| Difficulties with (yes; no) | | |
| Communication | 6.5 [0-9]; 5.8 [0-9] | 0.40 |
| Collaboration | 5.5 [0-8]; 6 [0-9.5] | 0.61 |
| Coordination | 7 [0-8.5]; 5 [0-9] | 0.27 |
| Accessibility | 6 [4-8]; 6 [0-9] | 0.69 |
| Presence of symptoms (yes; no) | | |
| Pain | 5 [0-9.5]; 7 [0-9] | 0.99 |
| Anxiety | 7 [1-9.5]; 5 [0.9] | 0.13 |
| Fatigue | 6 [0-9.5]; 5 [0.9] | 0.59 |
| Sadness | 6 [0-9.5]; 5 [0-9] | 0.23 |
| Constipation | 6 [2.5-9.5]; 5 [0-9] | 0.17 |
| Anger | 6 [0-9.5]; 5 [0-9] | 0.36 |
| Nausea | 7 [0-9.5]; 5 [0-9] | 0.04 |
| Dyspnea | 7 [0.5-9.5]; 5 [0-9] | 0.04 |
| Difficulties managing symptoms (yes; no) | | |
| Pain | 6 [0-9]; 5 [0-9.5] | 0.46 |
| Anxiety | 8 [6-9.5]; 6.5 [1-9] | 0.16 |
| Fatigue | 5 [0-9.5]; 6 [0-9] | 0.29 |
| Sadness | 6 [2.5-9.5]; 6 [0-9] | 0.92 |
| Constipation | - | - |
| Anger | 4 [0-8]; 6 [2.5-9.5] | 0.11 |
| Nausea | 6 [0.5-9]; 7 [0-9.5] | 0.52 |
| Dyspnea | 7 [1-8.5]; 7 [0.5-9.5] | 0.80 |

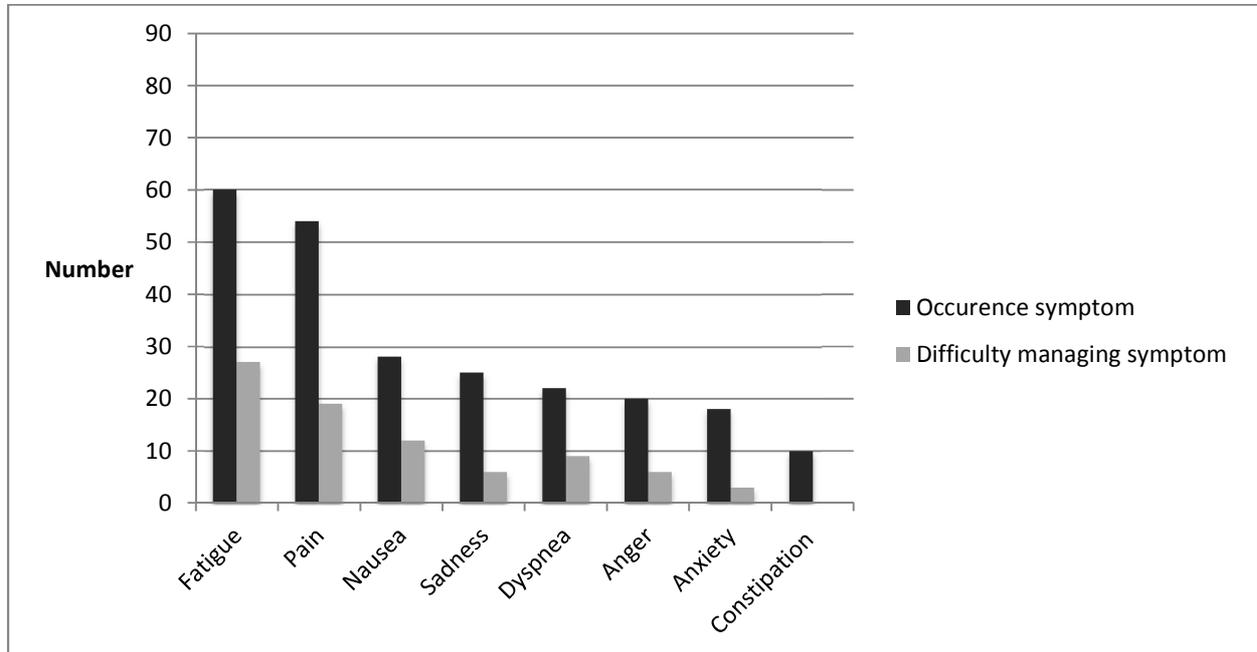
| | | |
|--|------------------------|-------|
| Supportive care not available in time | | |
| Yes; No | 7.5 [7-8]; 5 [0-9.5] | 0.16 |
| Moment of death | | |
| Expected vs. unexpected | 6 [0-9.5]; 4 [3-7] | 0.42 |
| Prepared vs. unprepared | 5 [0-9.5]; 5.3 [3.5-7] | 0.95 |
| Atmosphere around death (yes; no) | | |
| Beautiful | 5.5 [0-8]; 5.8 [0-9.5] | 0.64 |
| Restless | 7.5 [5-9.5]; 5 [0-9] | 0.007 |
| Calm | 5 [0-9]; 6.5 [0-9.5] | 0.34 |
| Shocking | 7 [4-8]; 5.5 [0-9.5] | 0.41 |
| Appropriate | 5.3 [1-8]; 6 [0-9.5] | 0.99 |
| Panic | 7.5 [7-8]; 5.3 [0-9.5] | 0.16 |
| Intimate | 6 [0-9.5]; 5 [0-9] | 0.46 |
| Hectic | 7 [2-8]; 5 [0-9.5] | 0.20 |

Figure 1. Flowchart of general practitioners (GPs) who participated in the study.

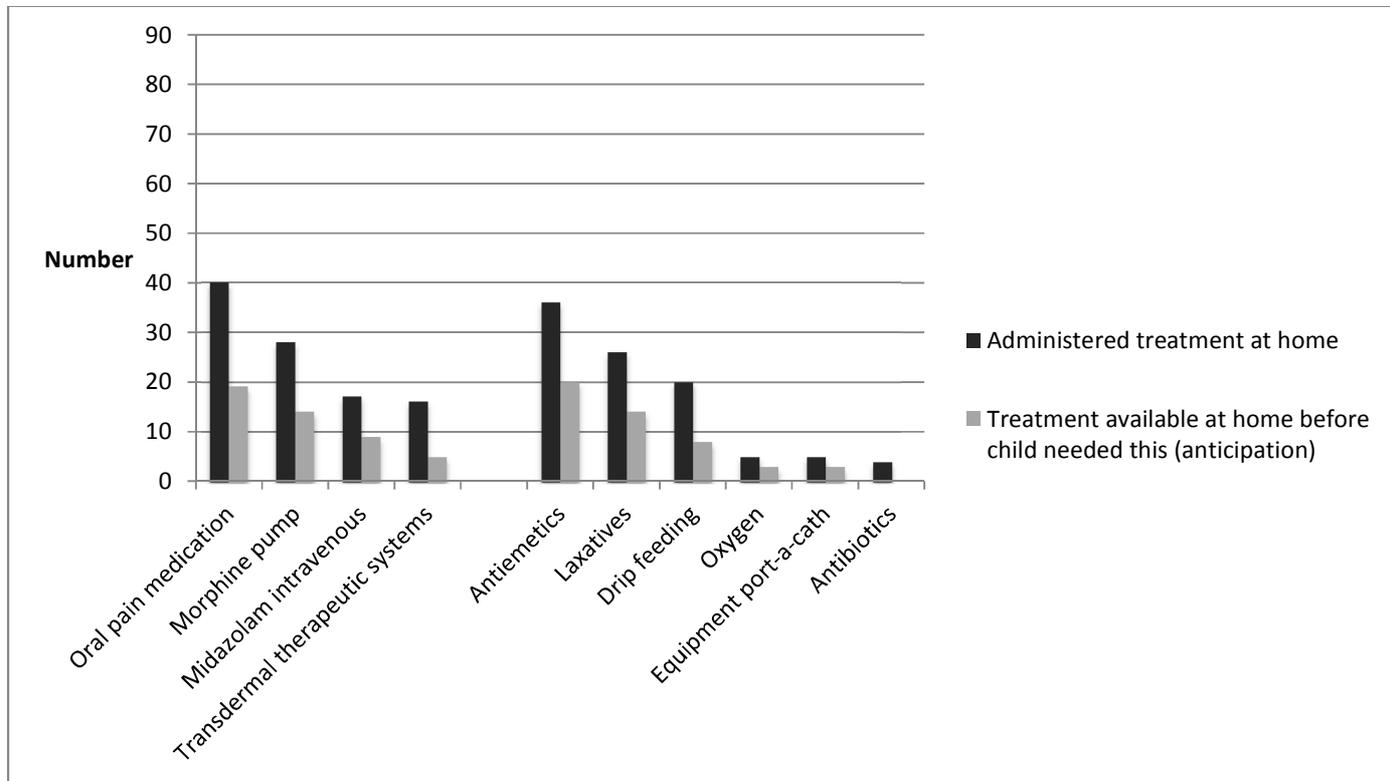
*= *Six GPs provided palliative care for two children.*

ACCEPTED MANUSCRIPT

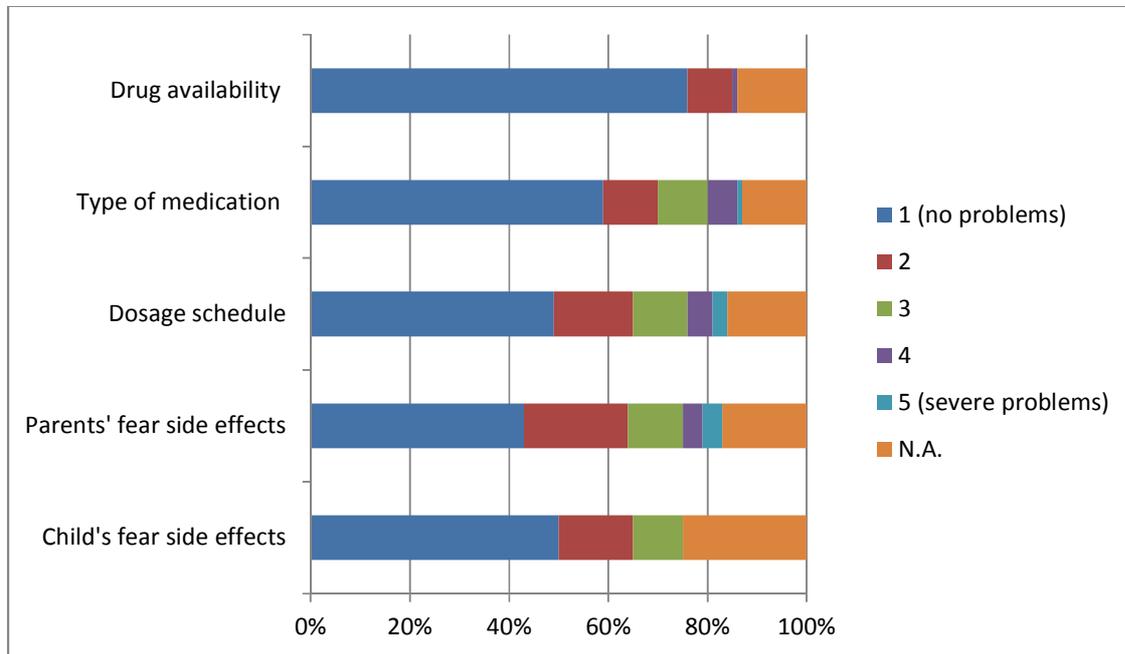
Figure 2. Summary of symptoms in children who received home-based palliative care, and the management of these symptoms.



Occurrence and difficulty managing the children's physical and psychological symptoms during the palliative phase (as reported by the treating GPs). Data are missing from 4 GPs. For calculating difficulty managing the child's symptoms, only the GPs who reported that the given symptom occurred were selected.

Figure 3. Summary of the palliative treatments administered at home.

Data from 5 GPs are missing regarding the treatments administered at home, and data from 3 GPs are missing regarding the treatments that were available at home before they were needed (anticipated).

Figure 4. Practical problems encountered with respect to pain medication.

Prevalence of practical problems encountered by GPs with respect to administering pain medication at home, as reported by the GPs. The indicated problems were rated on a five-point Likert score ranging from 1 (no problems encountered) to 5 (severe problems encountered). N.A. = not applicable or not known.