

# Aspects and Intensity of Pediatric Palliative Case Management Provided by a Hospital-Based Case Management Team: A Comparative Study Between Children With Malignant and Nonmalignant Disease

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## Abstract

**Objectives:** Anticipating case management is considered crucial in pediatric palliative care. In 2012, our children's university hospital initiated a specialized pediatric palliative care team (PPCT) to deliver inbound and outbound case management for children with life-shortening disease. The aim of this report is to gain insight in the first 9 months of this PPCT. **Methods:** Aspects of care during the first 9 months of the PPCT are presented, and comparison is made between patients with malignant disease (MD) and nonmalignant disease (NMD) in a retrospective study design. Insight in the aspects of care of all patients with a life-shortening disease was retrieved from web-based files and the hour registrations from the PPCT. **Results:** Forty-three children were supported by the PPCT during the first 9 months: 22 with MD with a median of 50 (1-267) days and 29 minutes (4-615) of case management per patient per day and 21 patients with NMD with a median of 79.5 (5-211) days and 16 minutes of case management per day (6-64). Our data show significantly more interprofessional contacts for patients with MD and more in-hospital contacts for patients with NMD. The median number of admission days per patient was 11 (0-22) for MD (44% for anticancer therapy) and 44 (0-303) for NMD (36% for infectious diseases). **Significance of Results:** This overview of aspects of pediatric palliative case management shows shorter but more intensive case management for MD in comparison with NMD. This insight in palliative case management guides the design of a PPCT.

## Keywords

palliative care, case management, pediatrics, palliative care team, end-of-life care

## Introduction

In the Netherlands, approximately 4200 children have a life-shortening disease and are therefore entitled to palliative care, with increasing prevalence reported.<sup>1</sup> These children can be grouped into 4 categories of palliative care, according to the World Health Organization (WHO) standards (Table 1).<sup>2,3</sup> When the child is at home, families need professional help to coordinate and warrant continuity of care.<sup>4,5</sup> General practitioners (GPs) obtain little experience in caring for a child with life-shortening disease and often feel unable to guide these families adequately. In this situation, parents might feel the urge to fulfill the tasks of a case manager to optimize care.<sup>6</sup> The literature exploits that a specialized pediatric palliative care team (PPCT) can be of great value.<sup>7</sup> Recent reports provide crucial information on the aspects of palliative care a PPCT should offer, such as availability at all hours, a multi-disciplinary structure, a liaison partner for continuity of care,

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**Table 1.** Four Categories of Palliative Care as Used by the WHO.

Category	Description	Examples
1	Life-threatening conditions for which curative treatment may be feasible but can fail	Cancer, irreversible organ failures of heart, liver, kidney
2	Conditions for which premature death is inevitable, where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities	Duchenne muscular dystrophy
3	Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years	Batten disease, mucopolysaccharidoses
4	Irreversible but nonprogressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death	Severe cerebral palsy, brain or spinal cord injury

Abbreviation: WHO, World Health Organization.

and advanced discussion of end-of-life topics. In addition, advance care planning with preferable documentation in an individual anticipated care plan,<sup>4</sup> the possibility of outpatient home visits, and bereavement support should be offered.<sup>4,8-16</sup> Currently, several merits of different types of pediatric palliative care services are documented in the literature, as summarized in Table 2. Documented benefits are less, and shorter hospital admissions,<sup>11,14</sup> an increase in children staying in preferred place of death when death occurred,<sup>10,12,13</sup> improved quality of life,<sup>4,8,14</sup> an increase in satisfaction with care,<sup>4,9,14,16</sup> and earlier discussions on do-not-resuscitate and end-of-life care.<sup>13</sup>

Monterosso et al have pointed out significant differences in care burden and health profile between children with malignant disease (MD) and nonmalignant disease (NMD).<sup>17,18</sup> They found that parents caring for children with NMD diagnoses experience a much longer caring trajectory, more parents were not working or working part-time, and a higher proportion were caring for more severely disabled children while parents with MD provided more assistance with mobility tasks. Furthermore, they show that parents with NMD would use a dedicated children's hospice for residential respite care compared to parents with MD who preferred to care for their children at home wherever possible. However, research on the differences in the needs of parents of children with MD versus NMD is still scarce.

Yearly about 35 children, who are treated for a life-shortening disease in our university hospital, die an expected

death. To optimally support this patient cohort as well as all patients in the chronic palliative phase of a life-shortening disease, a PPCT has been initiated in June 2012. In the development of the PPCT, all crucial aspects of pediatric case management as described in literature were combined (Table 2). The PPCT comprises specialized nurses who are experienced and trained in pediatric palliative care, child life specialists, a psychologist, a chaplain, and a social worker. The specialized nurses act as liaison case managers to organize palliative care for the patient. They coordinate the logistics of care supplied by all involved professionals. Every week the PPCT discusses patients in multidisciplinary conferences supported by 2 pediatricians and 2 pediatric oncologists connected to the team. Furthermore, the PPCT supports the first-line professionals, patients, and their families. The hospital-based PPCT bridges the gap between hospital and home by being the contact between parents and (primary) professionals.

A specific nurse specialist is assigned as the liaison case manager for the family and all involved health-care professionals. Upon introduction of the PPCT to a new patient by the treating physician, the liaison case manager will conduct an intake interview with patient and parents, usually at home, to establish a relationship and assess the required support. The nurse specialist will contact parents regularly, by telephone, mail, or house visits, to continuously evaluate the care provided, signal when more care or adjustment of care is required, and offer emotional support. The nurse specialist is the first contact person for all involved health-care professionals and coordinates all care for the child. After the intake has taken place, the nurse specialist introduces the patient in the multidisciplinary conference, and whenever needed, discusses the patient's care in depth. A structured individual anticipated care plan is constructed in cooperation with the medical specialist and provided to the parents and the primary health-care team, describing potential symptoms of the child's disease and complicating situations as well as the proposed interventions for these scenarios. By anticipating aggravation of symptoms, the child and its parents, as well as the primary health-care professionals, are prepared and can arrange necessary medication or supplies in advance.

Upon request, a paramedic and/or social worker and/or child life specialist can visit the child at home as well, either simultaneously with the nurse specialist or alone. A PPCT nurse specialist is available 24 hours a day to answer questions from parents, health-care professionals, and medical specialists, as described in the criteria by van der Plas et al.<sup>19</sup> In principal, the PPCT will not take over practical care from the primary health-care professionals (nurses and/or GPs) but will provide additional expertise and support in the form of consultation of other involved disciplines. In case of a calamity, the team is available to assist the primary health-care team with medical procedures such as introduction of a port-a-cath needle or urine catheter procedures.<sup>7</sup> With this initiative, expertise in pediatric palliative care will be offered in the primary health-care situation.

The aim of this report is to gain insight in the first 9 months of this PPCT, addressing the following questions:

**Table 2.** Overview of Different Components of Different Pediatric Palliative Care Teams.<sup>a</sup>

	Toce and Collins 2003 <sup>16</sup>	Golan 2008 <sup>10</sup>	Hays et al 2006 <sup>14</sup>	Vickers et al 2007 <sup>12</sup>	Wolfe et al 2008 <sup>13</sup>	Knapp et al 2012 <sup>8</sup>	Vollenbroich et al 2012 <sup>15</sup>	Gans et al 2012 <sup>14</sup>	Kline et al 2012 <sup>9</sup>	Arland et al 2013 <sup>11</sup>	Jagt et al 2017 <sup>27</sup>
Cohort	83 Children, NMD only	568 Children, MD only	41 Children; 34% MD, 66% NMD	164 Children, MD only	119 Children, MD only	98 Parents	43 Couples; 35% MD, 65% NMD	123 Children; 20% MD, 80% NMD	20 Parents, MD only	166 Children, MD only	43 Children; 22 MD, 21 NMD
PC team	Yes	Yes	Yes	No	Yes	No	Yes	No	Yes	No	Yes
Multidisciplinary	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	No	Yes
Home visits	No	Yes	No	Yes	Yes	NA	NA	NA	NA	Yes	Yes
EoL planning	Yes	Yes	Yes	Yes	Yes	No	NA	Yes	Yes	Yes	Yes
Advance care planning	Yes	NA	Yes	No	Yes	NA	NA	NA	Yes	Yes	Yes
Documentation tool	Yes	NA	Yes	No	Yes	No	No	No	Yes	Yes	Yes
Case manager	Yes	NA	Yes	Yes	Yes	NA	NA	Yes	NA	Yes	Yes
24-Hour availability	NA	Yes	No	Yes	Yes	NA	Yes	Yes	NA	No	Yes
Education	Yes	No	Yes	Yes	Yes	NA	NA	Yes	Yes	No	Yes
Organization of respite care	NA	No	No	No	No	Yes	NA	Yes	No	No	Yes
Bereavement support	Yes	Yes	No	Yes	Yes	NA	Yes	NA	NA	No	Yes
Reported positive effects of palliative care service	High parental satisfaction with care	Decrease in home deaths, earlier start of PC	Increased QoL and family satisfaction	Increase in home deaths	Early EoL documentation, earlier DNR discussion, more home deaths	Wide variety of parent reported HRQOL, lower levels of pain	High parental satisfaction, symptom improvement, increased QoL	QoL, decrease hospital admission days, reduction in costs	High parental satisfaction on team and DMT	Decrease hospital admissions	

Abbreviations: DNR, do-not-resuscitate; DMT, decision-making-tool; EoL, end-of-life planning; HRQOL, health-related quality of life; MD, malignant disease; NA, not available; NMD, nonmalignant disease; PC, palliative care; PCS, palliative care service; QoL, quality of life.

<sup>a</sup>This table provides an overview of the literature on evaluation of pediatric palliative care teams. Publications are retrieved from PubMed, EMBASE, PsycINFO, and CINAHL with publication dates from 2000 onwards. Documentation tool is some form of documentation tool containing information on end-of-life decisions and advance care management agreements, accessible for parents as well as all involved health-care professionals. End-of-life planning is an advance end-of-life decision-making with agreements on resuscitation, intensive care unit admission and preferred place of death. Advance care planning is an advance planning on all aspects of care, such as symptom treatment and pain medication. PC team is any form of specialized team or program initiated to deliver palliative care for children and their families.

- What aspects of case management are provided by the PPCT and in what intensity? Is this different for patients with MD versus NMD?
- What are the amounts, durations, and indications of hospital admissions and are there differences between children with MD and NMD?

## Methods

### Participants

All patients who received support by the PPCT between June 1, 2012, and April 1, 2013 were included in the study sample. Patients, aged younger than 18 years, with a treating physician from our center met the inclusion criteria. Patients treated in the neonatal intensive care unit were excluded. All treating pediatricians were asked to offer the team's support to any patient, admitted or treated ambulant, with a life-shortening disease. Patients were included on the date the PPCT accepted the patient. The PPCT does not support a patient on interval basis, so when a patient was introduced to the PPCT, support would be continued until death or until the end of the study period. "Aftercare" has been defined as the support starting on the day the patient died, until the family and the PPCT decided no more bereavement support was needed. If not ended earlier on the parents' request, aftercare will usually end after the second birthday after the child's death.

### Data Collection

The medical files were studied retrospectively to obtain the following data: patient and disease characteristics including age, gender, underlying disease, WHO category of palliative care, hospital admissions, and reasons for admission. Routinely, everyday a time registry of aspects of case management on every patient was performed by PPCT members as a part of their job, following a preset format to classify activities. The time spent on different aspects of case management (intake, support in the hospital, support at home, case management, consultation medical specialist, psychosocial department or other specialist multidisciplinary consultation, arrangement of materials, telephone family, telephone GP, traveling time, and aftercare) was reported in hours per patient as well as in minutes per patient per day. The number of hospital admissions was counted as well as the amount of admission days. For each patient individually, the ratio of admission days/days receiving support of PPCT was calculated.

The research ethics committee considered the study to be within the regulations of the Dutch Medical Research Involving Human Subjects Act, with no requirement to retrieve informed consent from neither the parents nor the PPCT members.

### Data Analysis

The data were analyzed using SPSS, version 20. Medical and sociodemographic characteristics were analyzed with

descriptive statistics. Differences between the aspects of patients with MD and NMD were assessed with  $\chi^2$  tests. The data were tested with a Mann-Whitney *U* test to assess differences between patients with MD and NMD. *P* values  $\leq .05$  were considered to be significant.

## Results

During the first 9 months, the PPCT provided support to 43 patients: 22 patients with MD and 21 patients with NMD. Patients with MD were introduced to the PPCT, a median of 147 (26-295) days after the start of the study, and patients with NMD, a median of 231 (33-295) days. The characteristics of the patients are depicted in Table 3.

### Aspects of Case Management

The time spent by the PPCT on different aspects of case management is presented in Figure 1. The PPCT spent a median of 21.78 (range 1.8-81.6) hours on case management of children with MD. For patients with MD, it came down to a median of 28.9 minutes of PPCT support per patient per day (range 4.2-615). The PPCT spent a median of 13.8 (range 0.5-50.7) hours on case management of children with NMD and a median of 15.8 (range 6-64) minutes per patient per day of PPCT support. Statistical analysis showed a significant difference in minutes of case management per patient per day of PPCT support ( $P = .030$ ) between MD and NMD. Most time was spent on support at home and in the hospital, aftercare, and on consultation of other health-care specialists (Figure 1). It appears that patients with MD received more support at home, whereas patients with NMD received more support in the hospital. Significantly, more time was spent on deliberations with the GP and medical specialist in children with MD in comparison with children with NMD ( $P = .023$  and  $.046$ , respectively).

### Hospital Admissions

Eleven (50%) of the 22 patients with MD were admitted to the hospital at some point during the study period. Among these 11 patients, a total of 25 admissions occurred and included a total duration of 121 days or an average of 4.8 days per hospital admission. Support by the PPCT for children with MD had a median of 99 days (range 5-267) during the study phase. The median ratio of admission days divided by days with support from the PPCT was 0 (range 0-1) for the MD group. Fifteen (71%) of the 21 patients with NMD were admitted to the hospital, with a total of 22 times. These hospital admissions came to a total of 353 days or an average of 16 days per hospitalization. The median of PPCT support of children with NMD was 76 days (range 5-211) during the study phase, with a median ratio of admission days/days of support from the PPCT of 0.08 (range 0-1). Statistical analysis revealed a significantly higher number of admission days for children with NMD ( $P = .029$ ), although the ratio of admission days/days with support from the PPCT showed no significant difference between MD and

**Table 3.** Characteristics of Children in Palliative Care.<sup>a</sup>

	Malignant Disease (n = 22)		Nonmalignant Disease (n = 21)		Total Patient Group (n = 43)	
	Alive	Deceased	Alive	Deceased	Alive	Deceased
Number of patients alive versus deceased	8	14	20	1	28	15
Gender (number of patients, male vs female)	4 m, 4 f	6 m, 8 f	12 m, 8 f	1 m	16 m, 12 f	7 m, 8 f
Duration of care in days, median (range)	99 (5-267)	41 (1-143)	72.5 (5-211)	95	72.5 (5-267)	44 (1-143)
Duration aftercare in days, median (range)		97 (0-169)		43		89 (0-169)
Death at home		13		0		13
Death in hospital		1		1		2
Distribution of patients across different WHO categories of palliative care (n)						
Category 1		22		0		22
Category 2		0		6		6
Category 3		0		1		1
Category 4		0		14		14
Diseases						
Central Nervous System tumor		14				
Other solid tumor		3				
Leukemia/lymphoma		2				
Bone tumor		2				
Neuroblastoma		1				
Metabolic		7				
Other congenital or genetic defects		7				
Neuromuscular		5				
Other		2				

Abbreviations: f, female; m, male; PPCT, pediatric palliative care team; WHO, World Health Organization.

<sup>a</sup>Duration of care is the amount of days the patient was supported by the PPCT during the study period. Duration of aftercare is the days of availability of the PPCT in which the family could receive support of the PPCT after the decease of the patient until formal closure of the support.

NMD. The major indications for admission were anticancer therapy (44%) for children with MD and infections (36%) for children with NMD. Both indications show significant differences between the 2 cohorts ( $P = .022$  and  $.025$ , respectively; Table 4).

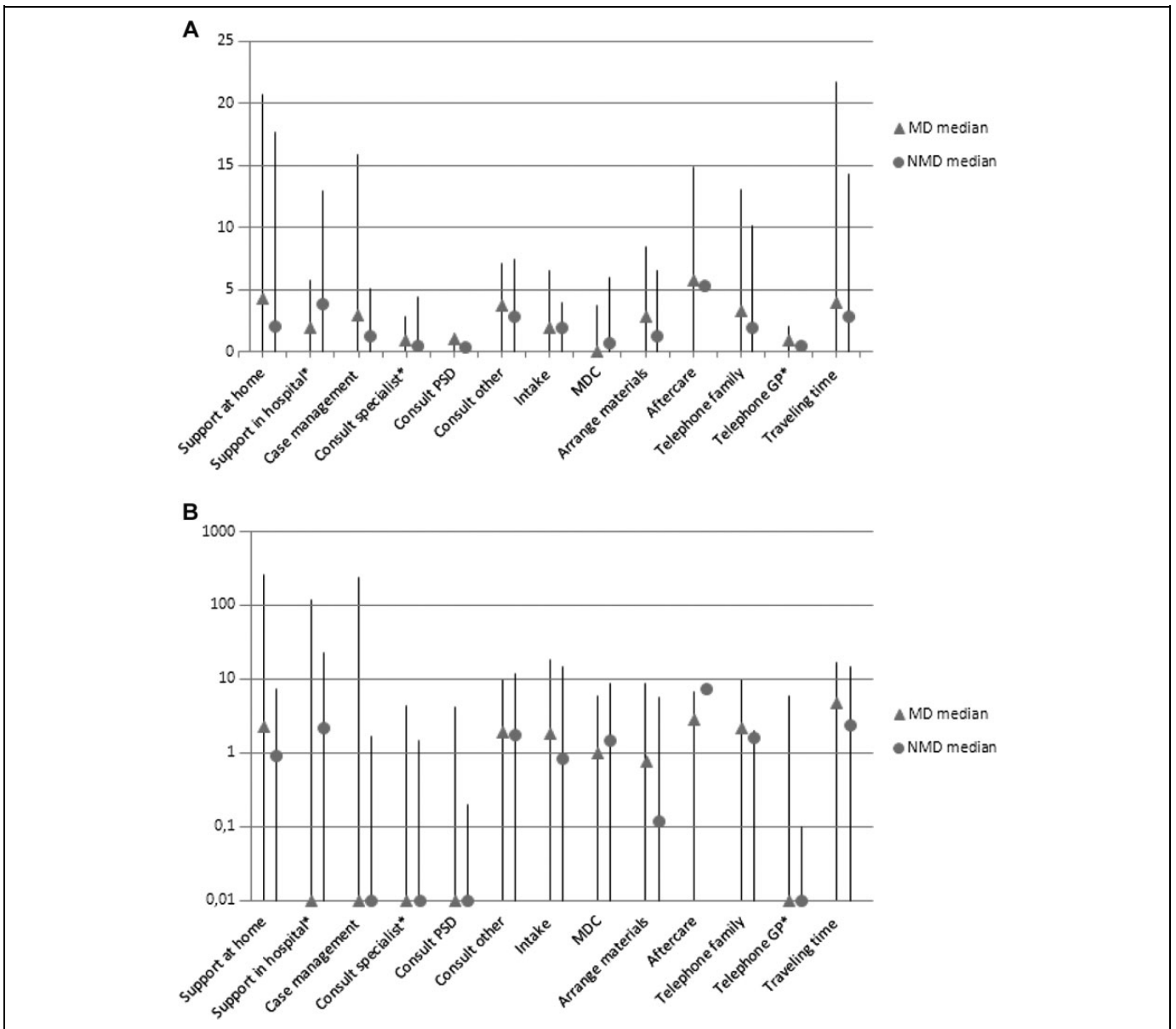
## Discussion

This report shows the aspects and intensity of pediatric palliative case management, as provided by the PPCT of our children's university hospital during the first 9 months. Results indicate that the 22 patients with MD are supported for a shorter period of time than the 21 patients with NMD, which is in line with the earlier research on the differences in palliative care between patients with MD and NMD.<sup>17,18</sup> Despite the WHO definition which suggests that any child with life-shortening disease should receive palliative care from the moment of initial diagnosis, it is a clinical practice in our hospital that a patient with cancer receives extensive supportive care until no curative options are left after which palliative care steps in.<sup>2</sup> The progressive nature of an incurable MD will result in a relatively short palliative phase and this clarifies the shorter support by the PPCT. In contrast, children with NMD are often entitled to palliative care earlier in the course of disease which leads to longer support. The irreversible aspect of NMD with a very likely premature death is usually evident upon diagnosis, and a chronic complex course of disease is

foreseen urging pediatric palliative care. For instance, children with metabolic disorders and/or congenital malformations require chronic support throughout their life.

Revising the amount of time case managers spent on each aspect of palliative care, it appears that children with MD are supported for significantly more minutes per day than children with NMD. This could be explained by the short but progressive terminal course of disease in children with MD after their referral to our PPCT, whereas children with a long chronic course of disease in NMD have a more variable intensity and need of support spread over more time. The study shows that significantly more time is spent on interdisciplinary contacts in the MD group, including the GP and the treating specialist. This could also emphasize the more intense support needed for children with MD in the palliative and terminal phase of life, requiring more interdisciplinary consultations for knowledge transfer and time spent on delivering continuity of care and information, also to the primary health-care system. On the other hand, more and longer admissions as shown for children with NMD might also contribute to this difference.

Children with NMD are hospitalized more often and longer and receive more support from the PPCT during their stay in the hospital than children with MD. This could be ascribed to the complex chronic course of disease in this group, requiring continuity in professional support especially during long admissions with many new intermittent care providers such as nurses, medical residents, and supervisors at the hospital.



**Figure 1.** Case management spent per patient and per day. The lines present the range. The dot and triangle present the median. The types of case management shown with an asterisk are found to be significantly different between patients with MD and NMD. A, The time that the PPCT spent on case management in hours per patient. B, The time that the PPCT spent on case management in minutes per day. GP indicates general practitioner; MD, malignant disease; MDC, multidisciplinary conference; NMD, nonmalignant disease; PPCT, pediatric palliative care team; PSD, psychosocial department.

However, the difference may also be invigorated by a form of inclusion bias. Long-term admissions might have triggered introduction to the PPCT, whereas patients who were not admitted during this phase might not have been introduced to the PPCT yet.

We initiated the first Dutch PPCT for case management. Since there is no data on the time spent on different aspects of case management in other countries, this study provides the first indication on how intensive the support of a palliative care team could be. It is important to know what aspects of case management and what intensity of care are needed for which patient for the design of a team. For patients with MD, it is

important that a case manager is available for a relatively short time, but with a high intensity, limiting the amount of patients 1 case manager can guide at the same time. For patients with NMD, case managers who can provide continuity of care for a longer period are needed, preferably for years.

Also, advanced care planning will be facilitated by this information on the patients' needs. This knowledge will allow the team to estimate tailored support for patients.

Moreover, insight in the time spent on case management will allow hospitals and insurance companies to perform a cost-benefit analysis. Benefits, such as decrease in hospital admissions, improved satisfaction and quality of life, and

**Table 4.** Hospital Admissions During the Palliative Phase.<sup>a</sup>

Patients and Admissions	Malignant (n = 22)			Nonmalignant (n = 21)		
	Patients	Admissions	Admission Days	Patients	Admissions	Admission Days
Total	11	25	121 <sup>b</sup>	15	22	353 <sup>b</sup>
Per indication						
Infection	3	6	30 <sup>b</sup>	9	12	178 <sup>b</sup>
Diagnostics	2	2	2	2	2	3
Respiratory support	0	0	0	3	3	46
Symptom treatment	2	3	15	3	3	114
Anticancer therapy	5	11	46 <sup>b</sup>	0	0	0 <sup>b</sup>
Transfusions	1	1	1 <sup>b</sup>	0	0	0 <sup>b</sup>
Social indication	1	1	12 <sup>b</sup>	0	0	0 <sup>b</sup>
Other (pneumothorax)	1	1	4 <sup>b</sup>	3	2	11 <sup>b</sup>
PICU admissions	2	2	2	6	7	124
Number of ED visits	4		4	3		3

Abbreviations: ED, emergency department; MD, malignant disease; NMD, nonmalignant disease; PICU, pediatric intensive care unit.

<sup>a</sup>The hospital admissions and their indications are listed for the subgroups MD and NMD and compared between the 2 patient groups.

<sup>b</sup>Number of admission days significantly different between patients with MD and NMD.

increase of the preferred place of death are described.<sup>4,9-14</sup> Reviewing our data, we may assume that the merit of the PPCT is achieved by the great amount of dedicated time the team can spend on the different types of consultation per individual patient. Since time registration is a routine part of the Web-based administration of the case managers, the likelihood of adequate time registration is high. Our data provide clear insight in the amount of time a case manager takes to support the patient and parents in their home and in the hospital, consult different specialists, arrange materials, and offer bereavement support. It is unlikely that a treating specialist will be able to spend this amount of time (a median of 30 minutes per day for children with MD and a median of 15 minutes per day for children with NMD) for each patient in the palliative phase of life-shortening disease. We assume that all additional time the case managers can spend per patient will directly relieve parents from organizational and practical tasks<sup>4,9,14</sup> and support them emotionally. This is in line with the results of Gans et al who concluded that the level of satisfaction increased after the start of a PPCT.<sup>14</sup> This might allow parents to spend valuable time with their ill child, potentially resulting in higher satisfaction and improved quality of life.<sup>4,14</sup> Furthermore, in the case managers' registrations, we see that for each patient who died, the case managers spent a median of 5 hours on aftercare, which comprised almost a quarter of all time spent on case management.

The anticipating nature of the coordination of care could result in the possibility of organizing more adequate support for the child at home, even in the terminal phase of the disease, possibly resulting in a decrease in hospital admissions and an increase in preferred place of death. In our cohort, most patients (13 of 15 patients) died at home, which might be facilitated by the PPCT, though our cohort is too small to draw conclusions. Although Arland et al describe a decrease in the amount and duration of hospital admissions, they do not report an increase in home deaths.<sup>11</sup> Wolfe et al and Vickers et al, however,

ascribe an increase in home deaths to the palliative care services.<sup>12,13</sup> In the Netherlands, home is most often considered as the preferred place of death.<sup>20</sup> The wish of patients and their parents to die at home may vary between countries and cultures. The literature on preferred place of death in children is scarce, and the available literature mainly reports parental information. Nonetheless, Bluebond-Langner et al performed a literature review which included some information on adolescents and young adults' opinion. Although most patients or their parents assigned home as the preferred place of death, some patients wish to die elsewhere.<sup>21</sup> Therefore, it is important to discuss this topic preferably with patients, otherwise with parents, early in the course of the palliative phase, and document the patient's and parents' wishes in the individual anticipated care plan.

Palliative case management also includes addressing the inexperience in delivering pediatric palliative care within the primary health-care team. This inexperience is inevitable, given the rarity of most life-shortening disease in children. There is extensive literature on the needs of children with NMD in both supportive and palliative settings<sup>22,23</sup>; however, the illnesses are heterogeneous with combined physical and psychological problems characterized by increasing complexity, level and types of functional limitations, and/or comorbidities and therefore require specific knowledge and types of health services.<sup>24</sup> The physical needs vary from pain management or mechanical ventilation to gastrostomy-tube feeding. Second, the psychological needs are addressed as important, such as dependency on others and feeling vulnerable.<sup>25</sup> Within all this, the family-centered care should be considered of great importance in the delivery of care to these children.<sup>26</sup> The wide scope of diseases makes it hard for home care nurses to gain knowledge in all diseases. A team, such as our PPCT can empower the primary health-care team through advice and education, providing a bridge between primary, secondary, and tertiary care.<sup>19</sup>

The conclusions we can draw from this study should still be taken with caution, due to the small study cohort, which is invigorated by classifying the cohort in different diagnoses. On the other hand, although it is known that the needs in palliative care for children with MD and NMD are different, research on these differences is scarce.

We provide detailed information on the time spent by the PPCT on different aspects of case management. We are nevertheless unable to report information on the content of delivered case management from this study. We have performed prospective research to investigate the content of support required for the fulfillment of different aspects of case management (for instance, practical, emotional, spiritual, etc).<sup>27</sup> A broader insight in the subjects of case management should also compare whether care needs differ between children with MD and children with NMD. Other factors that can influence the needs may be, but are not limited to, cultural preferences, geographical factors, patient's age, education level, and so on. These questions will be the focus of further studies on provision of pediatric palliative care.

Even though our study cohort is relatively small, from the data of our study, we conclude that the PPCT offers support for children and parents with life-shortening disease for a great amount of time per day. Patients with MD require more intensive support, for a shorter period, whereas patients with NMD are subject to long-lasting chronic case management. Furthermore, the PPCT has extensive contacts with all involved health-care specialists, facilitating interdisciplinary communication and reassuring continuity of care at home. Further study is warranted addressing the merits of a PPCT for patients, parents, and professionals.

### Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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