

Brief Report

Home-Based Palliative Care for Children With Incurable Cancer: Long-term Perspectives of and Impact on General Practitioners



Ivana M.M. van der Geest, MD, Patrick J.E. Bindels, MD, PhD, Saskia M.F. Pluijm, PhD, Erna M.C. Michiels, MD, PhD, Agnes van der Heide, MD, PhD, Rob Pieters, MD, PhD, Anne-Sophie E. Darlington, PhD, and Marry M. van den Heuvel-Eibrink, MD, PhD

Department of Pediatric Oncology and Hematology (I.M.M.v.d.G., S.M.F.P., E.M.C.M.), Erasmus MC-Sophia Children's Hospital, Rotterdam, The Netherlands; Princess Máxima Center for Pediatric Oncology (I.M.M.v.d.G., S.M.F.P., R.P., M.M.v.d.H.-E.), Utrecht, The Netherlands; Department of General Practice (P.J.E.B.), Erasmus MC, Rotterdam, The Netherlands; Department of Public Health (A.v.d.H.), Erasmus MC, Rotterdam, The Netherlands; Faculty of Health Sciences (A.-S.E.D.), University of Southampton, Southampton, United Kingdom

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. The objective of this study was 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 seven 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 health care 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. *J Pain Symptom Manage* 2017;53:578–587. © 2017 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Cancer, children, general practice, palliative care

Address correspondence to: Ivana M.M. van der Geest, MD, Princess Máxima Center for Pediatric Oncology, Lundlaan 6, 3584 EA Utrecht, The Netherlands. E-mail: i.vandergeest@erasmusmc.nl

Accepted for publication: September 25, 2016.

Introduction

Approximately 25% of children diagnosed with cancer die from the disease.¹ Compared with children with nonmalignant diseases, children with cancer are more likely to die at home.^{2–4} 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 health care models are possible in case children die at home, that is, hospital-based care or community-based care.⁶ The Dutch primary health care system is similar to several other countries in Europe, that is, the general practitioner (GP) functions as a primary health care professional.^{7,8} Palliative care in the Netherlands is generally embedded in general practice.⁹ Home death in the Netherlands, therefore, implies that care is delegated to GPs and community nurses, preferably supported by an experienced multidisciplinary pediatric 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 parents.¹² Moreover, poorly managed pain is associated with increased parental grief.¹³ 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 pediatric palliative care.^{14–16}

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 information.^{17–32} 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 10 GPs³⁰) or included randomly selected GPs²⁷ and emphasized the need for GPs to gain additional knowledge regarding pediatric palliative care.²⁷

Several studies reported how providing pediatric palliative care affects health care professionals.^{33–41} 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 to 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 on request, was reviewed by an independent GP. The questionnaire included topics such as the GP's demographic characteristics and 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 on 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. Nonparametric tests (the Mann-Whitney *U* test and the Kruskal-Wallis test) were used to compare the levels of distress across the GPs' demographic characteristics

Download English Version:

<https://daneshyari.com/en/article/5578269>

Download Persian Version:

<https://daneshyari.com/article/5578269>

[Daneshyari.com](https://daneshyari.com)