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# Managing diffuse intrinsic Pontine glioma (DIPG) through japan's pediatric home medical care (PHMC) system, originally designed for medically complex children

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## Abstract

**Background** Diffuse Intrinsic Pontine Glioma (DIPG) is one of the most aggressive and fatal pediatric brain tumors, with limited treatment options and a survival of less than two years. Therefore, palliative care plays a crucial role throughout the disease trajectory, yet home-based data remain scarce, particularly for pediatric patients. This study aims to describe the implementation of a pediatric home medical care system (PHMC) in Japan for children with DIPG, focusing on symptom management, care delivery patterns, and quality of life.

**Methods** We conducted a retrospective cohort study of 22 children with DIPG who received PHMC services from a single clinic in Tokyo between 2017 and 2024. Data were extracted from detailed medical records kept by physicians during home visits. We examined demographics, disease progression, end-of-life symptoms, medications (opioids, steroids), respiratory support, nutritional care, and frequency of home visits.

**Results** The average age at diagnosis was 7.9 years, with a mean overall survival of 14.2 months. Most children (91%) died at home. Major end-of-life symptoms included dysphagia, paralysis, respiratory distress, and convulsions. Steroids and morphine were the primary agents used for symptom relief. High Flow Nasal Cannula (HFNC) was used in 59% of cases. The physicians' visiting frequency increased significantly toward the terminal phase, with a maximum of 14 visits per month. Many children continued to attend school or engage in outings until shortly before death.

**Conclusions** The Japanese PHMC system, with physicians' home visiting, enabled comprehensive, hospital-level palliative care at home for children with DIPG. This model may serve as a framework for enhancing pediatric end-of-life care, especially where direct physician involvement is feasible. Our findings suggest the importance of structured, multidisciplinary home care systems in maintaining quality of life for children with terminal conditions.

**Keywords** Diffuse intrinsic pontine glioma, Pediatric oncology, Brain tumors, Palliative care, End-of-life care, Quality of life, Pediatric home medical care, Terminal care

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## Background

Diffuse intrinsic pontine glioma (DIPG) is one of the fatal diseases for children that results in death within 2 years after its onset. Anti-cancer drugs (chemotherapy regimens) do not improve overall survival [1–3], and the most effective treatment is radiation. Recent clinical trials using genetic approaches, including CAR-T cells, have succeeded in tumor regression [4]. However, in most cases, the early results have shown potentially severe side effects in the phase 1 trial [5]. Thus, a generally progressive course with worsening neurologic symptoms in DIPG, and understandably emotional distress in families, necessitates multidisciplinary support.

Veldhuijzen van Zanten et al. (2016) [6] and Hoffman et al. (2018) [7] described that while a cure has hardly been expected, palliative and end-of-life care [8] have been considered important in DIPG. Those papers described the disease-specific distressing symptoms and their evolution over time, and the interventions and services needed for holistic palliative and active end-of-life care as defined by WHO [9]. Veldhuijzen van Zanten et al. (2016) [6] included 63 DIPG patients in 2 hospitals in London, where all DIPG patients are introduced to the pediatric oncology outreach and palliative care team at the time of diagnosis. The team is composed of pediatric palliative care nurse specialists and consultants who work in partnership with pediatric oncologists at hospitals, and they provide supportive palliative care through the end-of-life phase and bereavement. Coleman et al. (2023) [10] also described that the involvement of a specialized interdisciplinary team would lead to best practices for DIPG.

In Japan, the Pediatric Home Medical Care (PHMC) system serves a similar role as these pediatric outreach and palliative care teams. In the PHMC system in Japan [11], a network is formed among hospitals, visiting physicians, visiting nurses, clinical psychologists, physical therapists, and pharmacists, and they collaborate to provide medical support for the child. Hospital-based physicians are neuro-oncologists, and in an emergency or in need of radiation/surgical operations, patients can use hospitals in this network. Home-visiting physicians are mainly pediatric/palliative care specialists who provide symptom diagnoses and treatments on-site. Hospital physicians and visiting physicians share patients' information and collaborate in a coordinated way.

Aozora Clinic in Tokyo, Japan, has functioned as one of the PHMC clinics since 2012, and has provided services to 22 DIPG children from 2017 to 2024. In every visit, details of patients' symptoms and procedures to ameliorate their discomfort as palliative and end-of-life care were recorded by visiting physicians.

In this paper, we aimed to provide information on DIPG patients under home care, their symptoms, treatments to ameliorate their sufferings, and what was important for their daily living at the end-of-life stage of DIPG.

## Methods

### Retrospective cohort study

To obtain disease-specific data, a retrospective cohort study using medical records was performed on all children (0–18 years old) with DIPG who received pediatric home medical care (PHMC) service from Aozora clinic (which covers the Tokyo metropolitan area and neighboring prefectures) between 2017 and 2024. The medical records of 22 patients were analyzed, who were diagnosed by MRI as DIPG in other hospitals and treated before they started to utilize the PHMC service.

## Demographic data

The age of patients was referred to as the age at the time of DIPG diagnosis. Overall survival (OS) was defined from the date of diagnosis to the date of death. The period of progression-free survival (PFS) was defined as a period during which symptoms improved or remained unchanged and could lead relatively good condition without major disturbing conditions. However, it was measured only for the period after PHMC started, as information on the PFS during hospital treatment was not available.

## Symptoms and treatments

Symptoms and treatments in hospitals were extracted from medical information forms sent from the hospitals, and the main medical procedures in hospitals were listed as radiation, anti-cancer drugs, central venous (CV) catheters, and ventriculo-peritoneal (VP) shunts. End-of-life symptoms and treatments were extracted from the medical records of our clinic during the period of the last 3 months till death. The usage of anti-cancer drugs, steroids, opioids, anti-psychiatric drugs, high-calorie infusion (total parenteral nutrition), and high flow nasal cannula (HFNC) was listed.

## Results

### Demography

The demography of 22 patients (male: 9, female: 13) is shown in Fig. 1. The age of diagnosis was 7.9 ± 3.3 years old (male: 8.2 ± 4.1, female: 7.7 ± 2.6 years old) (Fig. 1A), OS periods was 14.2 ± 7.2 months (male: 16.3 ± 9.7, female: 12.7 ± 4.9 months) (Fig. 1B), period of PHMC was 6.8 ± 5.6 months (male: 9.8 ± 6.8, female: 4.5 ± 3.3 months) (Fig. 1D), age of death: 9.1 ± 4.3 years old (male: 9.6 ± 4.3, female: 8.8 ± 2.7 years old). As for the location of death, 20 cases died at home, and 2 cases died at hospitals due to emergency hospitalization.

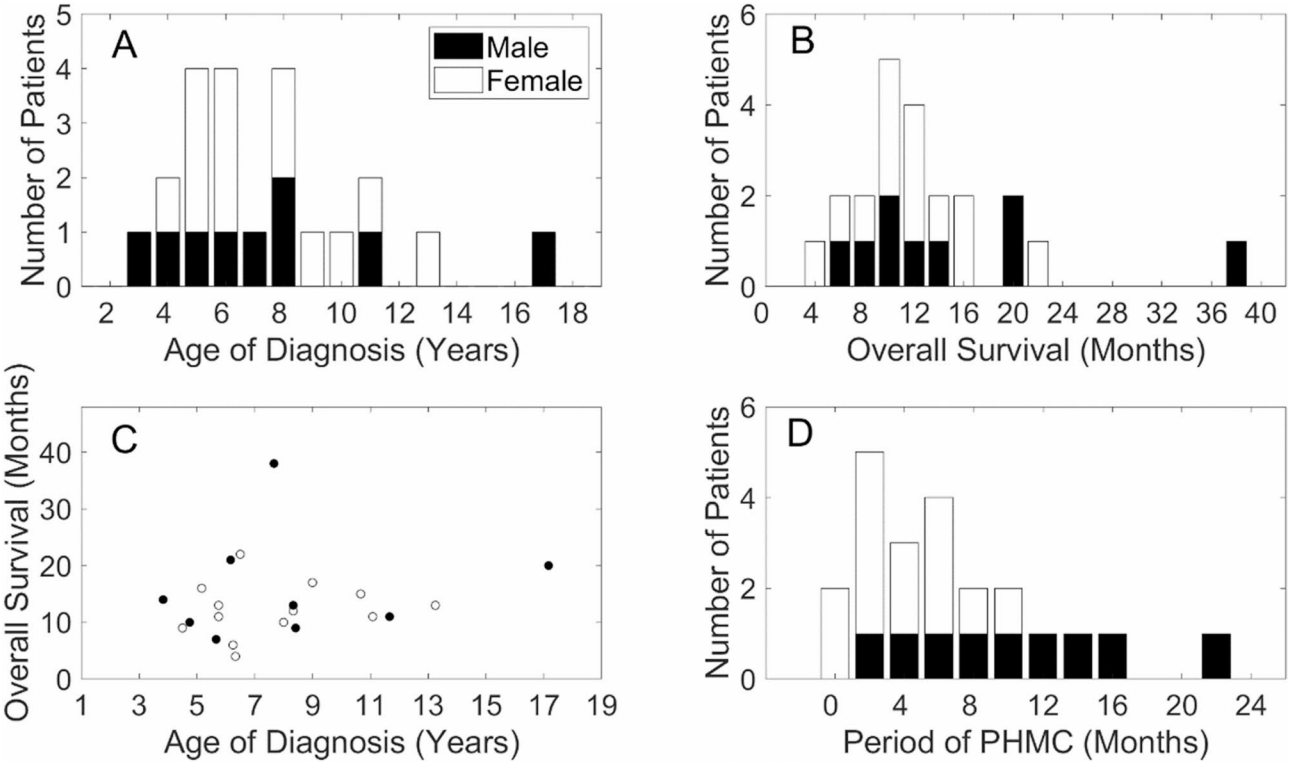


**Fig. 1** Demography of 22 patients. A indicates the age when they were diagnosed. B shows the distribution of OS (overall survival). C shows the correlation between the age of diagnosis and OS. D shows the period from the start of PHMC to the death

In terms of PFS, 8 cases had no PFS after starting PHMC, and 14 cases had PFS periods that varied from 1 to 10 months, with a mean of 5.8 ± 3.5 months.

#### Diagnosis (documented in medical information forms from the hospitals)

In all 22 cases, DIPG was diagnosed by MRI. Biopsy was performed only on 5 cases, in which the genotypes of 4 cases were identified as 3H27K-altered, and in 1 case, genotype information was unavailable.

Initial symptoms documented in medical information forms from hospitals included: left abducens paralysis ($n = 8$), abnormal eye position ($n = 3$, "side" was unidentified), facial nerve paralysis ($n = 6$; with left side ($n = 2$) and side was unidentified ($n = 4$)), dysphagia ($n = 5$), dysarthria ($n = 4$), cerebellar symptoms such as staggering ($n = 6$; with left cerebellum ($n = 1$), and side was unidentified ($n = 5$)), upper and/or lower limbs paralysis ($n = 5$; with right-side dominant ($n = 4$), and left-side dominant ($n = 1$)). It was noticeable that left-sided brainstem symptoms as initial signs were observed more frequently.

### Symptoms at the beginning of the PHMC

The time course of patients' conditions, including the timing of the start of PHMC, is shown in Fig. 2. The graph is aligned with the timing of the start of PHMC. Right side bars indicate the PHMC period from the beginning of PHMC till death, and left side bars indicate the periods at hospitals before the start of PHMC. The numbers at the center of bars indicate patients' age when the PHMC started. Some patients were introduced to PHMC during PFS, while some were introduced after their symptoms became severe. Observed symptoms at PHMC were as follows; abducens nerve paralysis ($n = 10$; with left ($n = 4$), bilateral ($n = 1$), and side unidentified ($n = 5$)), facial nerve paralysis ($n = 7$; with left ($n = 4$), right ($n = 1$), and bilateral ($n = 2$)), limb movement disorder/paralysis ($n = 10$; with right ($n = 5$), left ($n = 1$), and bilateral ($n = 1$)), speech Impairment ($n = 4$), dysphagia / Inability of oral intake ($n = 4$), headache ($n = 4$), and vomit ($n = 3$). Even at the stage of PHMC introduction, symptoms due to the left brainstem lesion seemed to be dominant. The difference in anatomical and genetic laterality was reviewed by Cini et al. (2024) [12] and Ellingson et al. [13] in glioblastoma, and by Inskip et al. (2003) [14] in gliomas. In terms of DIPG, such laterality has not been reported. One noticeable point is that the initial symptoms caused by left brainstem lesions were observed more frequently than by right brainstem lesions. However, due to the small number of our cases, it was not conclusive. In the future, if the number of DIPG cases increases, information about the initial laterality of DIPG might become clear.

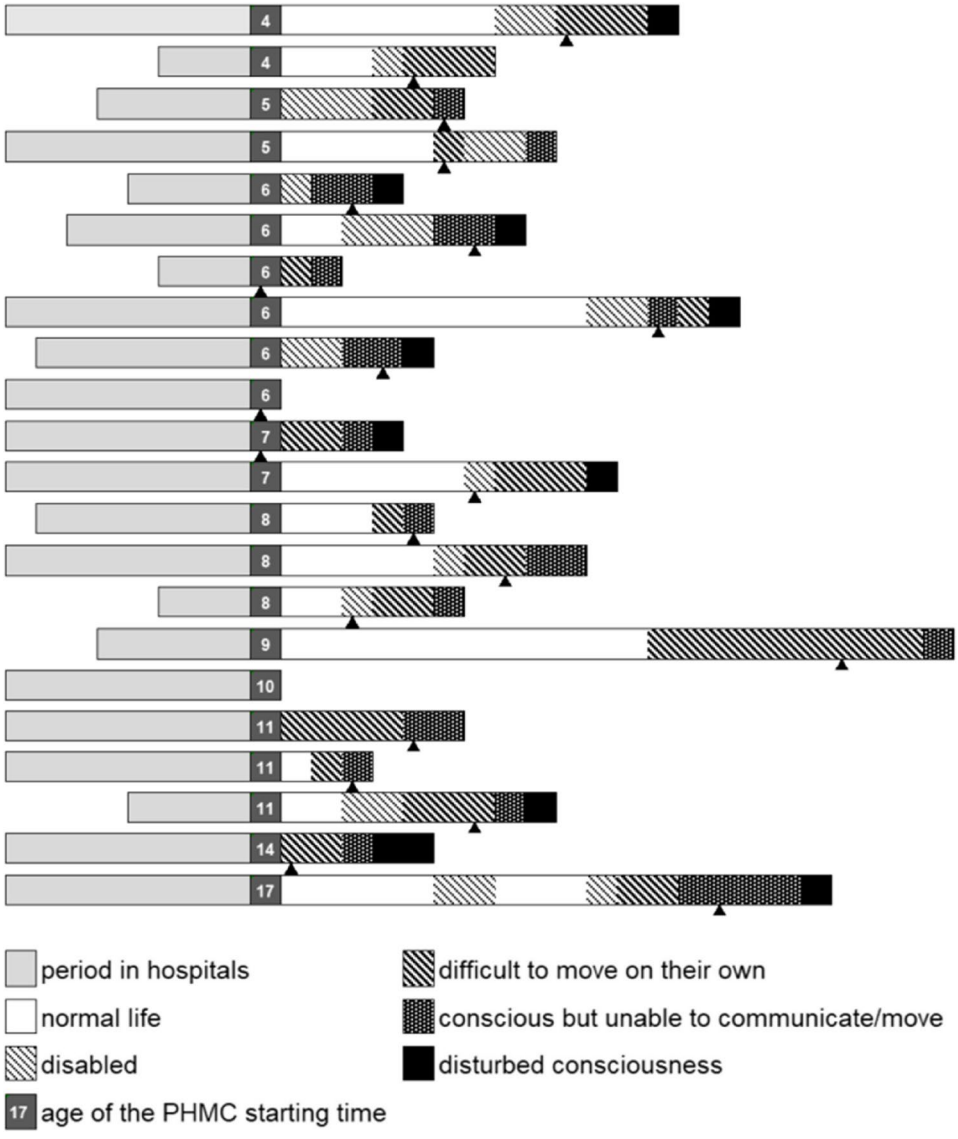


**Fig. 2** DIPG disease course (from diagnosis, left edge) to death (right edge). The timing is aligned at the start of PHMC (Dark-shaded column at the center, of which numbers indicate the age at which PHMC started.) One box indicates 1 month. The gray areas on the left indicate the periods of hospital stay. Blank areas indicate PFS, and shading gradients indicate levels of disease condition (the darker the shade gets, the worse the patient's condition was). Arrowheads indicate the last time they went out

## Treatments at hospitals and with PHMC

Treatments that require monitoring of general conditions were performed at hospitals before and after PHMC started. A list of treatments is shown in Table 1. Thirteen patients received radiation one time: 54 Gy/30Fr, 8 patients had 2 times radiation (the 2nd time was 30 Gy/10Fr, 33 Gy/15Fr), and 1 patient had 3 times radiation therapy. Among those who had radiation, 4 patients were treated with a proton beam, one with a gamma knife, and the rest with intensity modulated radiation therapy (IMRT) or volumetric modulated arc therapy (VMAT). There was no significant difference ($p = 0.8834$) in OS between groups with 1 time ($n = 13$, OS = 13.6 ± 8.3 months) and 2 times radiation ($n = 8$, OS = 13.1 ± 5.2 months).

The number of patients with a VP shunt was 7, and with CV catheters including peripherally inserted central catheter, was 14. For the treatment of dysphagia, CV catheter, gastric fistula, and nutritional component infusion (total parenteral nutrition) were effective. As anti-cancer drugs, Temozolomide, Bevacizumab, Methotrexate, and Etoposide were used: 13 patients were treated by one or a combination of two anti-cancer drugs, while none were prescribed in 9 patients. Among those treated by the anti-cancer drugs, in 4 cases treatment continued till 3 months before death, in 7 cases until 2 months before death, and in 2 cases until 1 month before

Table 1

| | Biopsy | Radiation | VP shunt | CV catheter | *Chemotherapy | Clin.Trials | NKT cell |
|---|---|---|---|---|---|---|---|
| n | 5 (4:H3K27mutant 1:unknown) | x1=13 (3 with positron) x2=9 (1case: 1st time: positron; 2nd time: gamma knife) x3=1 | 7 | 14 | Treated =16* None=7 | 4 | 2 |

***Chemotherapy**

| Anti-cancer drugs | Temozolomide (TMZ) only | Bevacizumab (BEV) with Methotrexate | TMZ+BEV | Etoposide (ET) only | TMZ later switched to ET |
|---|---|---|---|---|---|
| n | 3 | 1 | 8 (1: with nivolumab) | 3 | 1 |

Table 2

In the period from 3 months before death to the time of death

| Drugs | Glycerol (for increased brain pressure) | High-calorie infusion | Anti-psychotics (**In several cases, multiple drugs were used at different time points for the same patients) | Anti-convulsants |
|---|---|---|---|---|
| cases | 9 +(2 at hospital) | 14 +1 (gastric tube) | 14 ** Anxiety: Diazepam(2), Bromazepam (5) Risperidone (1) Haloperidol (4) Quetiapine+Sertraline (1) Olanzapine (1) Sleep disorder: Ramelteon (4), Midazolam (4), Suvorexant+Zolpidem (1), Chloral hydrate (1) | Midazolam (1) Levetiracetam (7) Midazolam with Levetiracetam (2) Fosphenytoin (1) |

| Device | Urinary catheter | Wheelchair | HFNC |
|---|---|---|---|
| cases | 5 | 14 | 13 |

death. Four patients participated in medical trials of new medications but had to stop them as their general conditions worsened. Two patients participated in NKT cell immunotherapy, but the treatment was stopped without completing the course due to their worsening general conditions.

### Symptoms and treatments in the 3 months before death with PHMC

After starting PHMC, some patients continued to lead a relatively stable life, although their conditions gradually worsened. We describe the symptoms and treatments that were applied to each condition in the last 3 months of their life, as these could serve as an example of palliative care for DIPG children. The most frequently occurring symptoms and treatments (Medications / Devices) in the last 3–5 months toward the terminal stage were shown in Table 2 and in Supplementary Table S1.

At the increase of the cerebrospinal fluid pressure, Glycerol was infused either in hospitals ($n=2$) or in PHMC ($n=9$). When dysphagia progressed, high-caloric infusion was applied via CV catheter, intravenous or subcutaneous injection ($n=14$), and gastric tube ($n=1$). Convulsion was treated by anti-convulsant drugs ($n=12$), and psychotic symptoms, such as anxiety or insomnia, were treated by anti-psychotic medications ($n=14$). High Flow Nasal Cannula (HFNC) was used to ease respiratory difficulties in 13 cases. For urinary problems, a urinary catheter was used in 5 cases (22.7%).

### Steroids and morphine are major medications to Sedate patients of DIPG

These medications were used when pain and respiratory difficulties were severe. In 20 cases, Dexamethasone was used from 1 mg/day to 6.6 mg/day regardless of patients' body weight (Supplementary Table S2), mainly for ameliorating headache and respiratory difficulties. Opioids (Morphine or OxyContin) were used in 6 cases when all other analgesic medications were ineffective (Supplementary Figure S3). The doses were from 1 μg/kg of body weight/hour to around 200 μg/kg of body weight/hour, depending on their conditions. Caregivers were instructed to press the patient-controlled analgesia (PCA) button to deliver a rescue dose if patients showed signs of pain (such as high blood pressure, tachycardia, etc.)

### Last Out-Going and feedback from families

For many of the DIPG children in our clinic, going to school was very important, and they were eager to go to school as much as possible. As shown in Supplementary Table S4, in 16 cases, they went out in the range of 0.4 to 5 months (average 2.5 months) before death, and in 4 cases, they went out from 5 days to 1 day before death. In 2 cases, patients had no time to go out. Most of the places they went were schools (9 cases) or theme parks such as Disneyland (7 cases). It seems very important for most of them to be at school, although a few patients did not want to go to school, as they did not like to be seen by their classmates. In many cases, patients were willing to and were very pleased to go out with their families or see their schoolmates, and this would be difficult if they remained in hospitals throughout the disease. Based solely on the description of the medical records, ten families stated that it was very good for them to be able to stay with and care for the child at home until the end of life, which, in hospitals, is the work of nurses, and family involvement is much less. Two families were unsure whether to stay at home or be hospitalized, but felt reassured to choose PHMC after understanding the close collaboration between our clinic and the hospitals. In addition, physicians still maintain contact with 12 families and have interviews from time to time even after the child's death, which may indicate the trust from patients' families in PHMC.

### Visiting frequency

In the PHMC system in Japan, the visiting frequency of physicians per day is not limited. Therefore, physicians can provide treatments at home as much as needed. As a consequence, the visiting frequency increased along with the worsening of patients' conditions. In a stable condition, visiting frequency was twice or three times a month. However, the last one month before death, the visiting frequency increased up to 14 times/month (average = 6.7 times/month). The visiting frequency tended to increase to monitor the children's condition if they were treated with morphine.

## DISCUSSION

### Symptoms and treatments in each phase of DIPG

In this paper, we described symptoms and measures to ameliorate the pain of DIPG children at home. The disease course of DIPG takes the same time course described by Veldhuijzen van Zanten et al. [6], starting from abnormal eye movement, motor dysfunction, paralysis of limbs, dysarthria, dysphagia, respiratory disorders, and a decrease in consciousness level.

At hospitals, after the diagnoses by MRI and genetic analysis, patients were treated with radiation and anticancer drugs as routine procedures. In one case, the patient and the patient's family did not want any aggressive treatments, and only radiation was performed.

After patients were introduced to our home care system, we provided treatments to maintain their general condition and to decrease their pain and suffering (palliative care). Meanwhile, patients had regular visits to their hospitals and visits for anti-cancer drug administration. If necessary, patients were hospitalized for surgeries. Their hospitals and home-care providers communicate closely and discuss patients' conditions and their needs, to provide appropriate care depending on the stage of illness. Toward the end-of-life, the frequency of home care visits increased mainly to provide sedation for suffering and to support their family members. Steroids and morphine are major medications to sedate respiratory difficulty and general pain, and are broadly used in Japan. In the terminal stage of DIPG, these two types of medication seemed to be effective in ameliorating patients' sufferings.

### Benefits of PHMC in DIPG

Before the establishment of PHMC, children with DIPG in Japan generally received conventional hospital-based care. With PHMC in collaboration with hospitals, we can provide hospital-level palliative support at home and continuous care for both patients and families. In our cohort, OS was approximately 14 months, slightly longer than the commonly reported median of ~ 11 months [15, 16]. Given the small sample size, however, this difference is not statistically significant. Further studies with larger cohorts will be necessary to clarify whether this model not only helps preserve quality of life but may also contribute to prolonged survival.

Intensive palliative care at home allows the child to stay at home and go out until the end of life. Being in a familiar place with their family and being able to go to school or preschool are probably the most important factors in these children's lives, and in some cases, patients were willing to go to school even several days before death (Supplementary Table S4). Going through days in an ordinary schedule might be a great benefit for patients, providing them stability, and seems to help maintain their quality of life (QOL).

In the Japanese national health care system, it is possible to have both hospital access when needed and visits by physicians at home, which also provides a sense of security for caregivers. At hospitals, they can get radiation therapy, anti-cancer drugs, major surgical operations (tumor resection, VP shunt, and setting a CV catheter), and emergency hospitalization. With the PHMC system, they receive daily medical support such as pain relief (analgesics, steroids, and morphine), respiratory maneuvers (suction of phlegm, HFNC, steroids, morphine), anti-emetic treatments, laxatives, neurological/

psychological medications, urinary catheterizations, and anti-inflammatory treatment (Supplementary Table S1).

In systems in the USA and European nations, generally, physicians stay at hospitals and provide directions for medical procedures to visiting nurses via a remote access system. There are differences in pediatric palliative care depending on the healthcare systems of each nation [17, 18]. It also depends on geographical limitations, such as the travel distance between physicians and patients. In Japan, physicians' visiting patients' homes is possible, because, particularly in cities, where the travelling distance is short enough that one physician could visit multiple patients a day. In that sense, the PHMC system seems to function in populated regions. However, according to recent developments in Hospital at Home (HaH), it might be possible to provide similar services. Particularly in countries where distances between houses are large and travelling from one patient to another would take a long time, HaH service might be better.

The Japanese home healthcare system is designed so that physicians visit patients' homes at least 1–2 visits/month. In addition to physicians' visits, visits by dentists, nurses, physical therapists, occupational therapists, speech therapists, and pharmacists are also supported by the national health insurance system. If the patient's condition becomes severe and requires frequent treatments, such as the end-of-life stage in DIPG, a high frequency of physicians' visits is allowed and supported by public health insurance without limitation. This will contribute to assuring the quality of care and patients' peace of mind.

Another benefit of the physician's visit is that they can take a precise medical record on site. Veldhuijzen van Zanten et al. (2016) [6] described in their paper, "Future studies should therefore include prospective registration of DIPG-specific symptoms, from diagnosis and throughout the disease trajectory, and accurate recording of applied interventions and their effect on symptoms and quality of life". Although our study is not prospective, our medical records were precise, including hospital diagnoses and treatments, temporal changes in conditions with treatments, and active treatments in the end-of-life phase. We suppose our information could be useful in establishing general guidelines for DIPG patients under home healthcare. Still, we "need to develop evidence-based, standardized disease-specific (multi-) institutional and (multi-) national palliative care guidelines for DIPG patients" [6].

Recently, the concept of Hospital at Home has been developed [19, 20]. In many cases, physicians usually support patients from hospitals with remote supervision, and visiting nurses and other agents visit patients' homes to provide treatments under physicians' supervision. In the Japanese home medical system, physicians have direct contact with patients at home. This system could provide one type of model for the future development of Hospital at Home.

## Conclusions

The Pediatric Home Medical Care (PHMC) system in Japan enabled comprehensive, hospital-level palliative care for children with DIPG in their homes. This model supported symptom management, maintained quality of life, and allowed families to remain together through the end-of-life period. Our findings suggest that systems integrating direct physician visits with flexible, multidisciplinary home care may be highly effective for terminal pediatric conditions. The PHMC model could serve as a foundation for future developments in pediatric home-based palliative care for the terminal stage of cancer.

**Figures and Tables**.

**Figure 1**.

**Figure 2**.

Table 1.

Diagnosis and treatment at hospitals before starting PHMC. Details of chemotherapy is shown in the lower table (*Chemotherapy).

Table 2.

List of palliative care (drugs: upper table and devices: lower table) in the last 3 months before death.

**Abbreviations**

| | |
|---|---|
| CAR-T | Chimeric Antigen Receptor T-cell |
| CV catheter | Central venous catheter |
| DIPG | Diffuse intrinsic pontine glioma |
| HaH | Hospital at Home |
| HFNC | High flow nasal cannula |
| IMRT | Intensity-modulated radiation therapy |
| MGMT | O6-methylguanine-DNA methyltransferase |
| MRI | Magnetic resonance imaging |
| NKT | Natural killer T |
| OS | Overall survival |
| PCA | Patient-controlled analgesia |
| PFS | Progression-free survival |
| PHMC | Pediatric home medical care |
| PTEN | Phosphatase and tensin homolog |
| QOL | Quality of life |
| TP53 | Tumor protein p53 |
| VMAT | Volumetric modulated arc therapy |
| VP shunt | Ventriculo-peritoneal shunt |

## Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12904-025-01887-z.

Supplementary Material 1

**Acknowledgements**

This study focuses on DIPG, a highly aggressive and devastating disease. All participating children have sadly passed away. We are deeply grateful to their families for supporting this research despite their profound loss. We also extend our heartfelt thanks to the children and their families, whose strength and trust made this study possible; to the medical professionals involved in both home-based and hospital-based care for their dedicated

and compassionate support; and to the hospitals that kindly referred these patients to our clinic.

**Author contributions**
TO, MY, NI, II, MI, and HM conceptualized the work presented in this manuscript. MI and II provided the data based on the medical records. TO, MY and NI had analyzed and verified the data reported in the manuscript and TO, MY, NI and HM interpreted the results. MY and NI have drafted the work and generated figures and tables. TO and HM revised the manuscript. All authors read and approved the final manuscript.

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**Data availability**
The data supporting the findings of this study are available from the corresponding author upon request. However, individual patient data are not publicly available due to the Act on the Protection of Personal Information in Japan.

## Declarations

**Ethics approval and consent to participate**
This study was approved by the institutional clinical research review boards of the National Center for Child Health and Development (approval number: 2024-067, December 11, 2024). The study was conducted in compliance with the Declaration of Helsinki and the Ethical Guidelines for Medical and Biological Research Involving Human Subjects issued by the Ministry of Education, Culture, Sports, Science and Technology (MEXT); the Ministry of Health, Labour and Welfare (MHLW); and the Ministry of Economy, Trade and Industry (METI) of Japan.

**Consent for publication**
Not applicable.

**Competing interests**
The authors declare no competing interests.

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