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(Citation)

The Kobe journal of the medical sciences, 58(2):33-40

(Issue Date)

2012

(Resource Type)

departmental bulletin paper

(Version)

Version of Record

(JaLCD0I)

<https://doi.org/10.24546/81003962>

(URL)

<https://hdl.handle.net/20.500.14094/81003962>



Place of Death of Pediatric Cancer Patients in a Single Institute during 7 Years

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Received 21 October 2011/ Accepted 26 January 2012

Key Words: place of death, preference, pediatric cancer patient, factors influencing place of death

ABSTRACT

Place of death is an important issue at the end-of-life. It is poorly understood in pediatric cancer patients in Japan. This study aimed to clarify place of death of children with cancer as well as variables associated with place of death.

Study population was pediatric cancer patients who died in the Department of Pediatrics at Kobe University Hospital during the last 7 years. The medical records were retrospectively reviewed regardless of cause of death to derive data relating to patients' characteristics and disease.

18 patients were included. Median age at death was 12.2 years old. 6 patients including 5 children in complete remission had hematological disease and 12 patients suffered from solid tumors.

4 patients (22.2%) died at home, whereas 14 patients (77.8%) died in the hospital including 6 ICU deaths. No one died in hospices. Preference of patients was unavailable due to the lack of inquiry. Factors influencing place of death (home, ICU, non-ICU) were disease (hematological disease vs. solid tumor, $p=0.010$, brain tumor vs. non-brain tumor, $p=0.023$), disease status (complete remission vs. non-complete remission, $p=0.0014$) and preference of families ($p=0.029$). Among 6 families who expressed preference, no disparity was observed between actual and preferred place of death.

This is the first English publication of place of death of pediatric cancer patients in Japan. The low percentage of home death, factors influencing place of death and the lack of disparity between actual and preferred place of death were indicated. Further studies are required to better understand place of death.

INTRODUCTION

Place of death is considered as an indicator of end-of-life care(6). However, the previous studies have reported the disparity between preferred and actual place of death(1). Place of death has been rigorously studied to perceive current reality of place of death and identify the factors that influence on place of death in order to reduce the disparity.

According to Gomes et al, place of death is influenced by some factors; individual factors, environmental factors and health factors(5). The study on place of death contributes to detection of those factors influencing place of death and health care strategies based on those factors may promote the concordance between actual and preferred place of death.

Moreover, the optimal allocation of health care resources, which is necessary in the society with increasing health care cost(3), may be feasible based on the result of studies. Home death is preferred among half of Japanese cancer patients(11), and it should be encouraged for cancer patients who desire to die at home as it is resource-friendly compared to hospital death that has been increasing recently(1).

Place of death has been studied among adult cancer patients, however, that of children with cancer is under-investigated(8). In Japan, only 1 study was conducted. The study on place of death targeting pediatric cancer patients is required due to the differences in circumstances around cancer treatments between children and adults.

Commonly, death certificate is reviewed to derive data such as place of death and disease in the retrospective studies on place of death. It enables large study population. However, data of variables that may influence place of death such as preferred place of death are unavailable on death certificate(5).

This study aims to reveal actual and preferred place of death of pediatric cancer patients and to identify the factors influencing place of death. Therefore, it was determined that medical records would be appropriate rather than death certificate as a data source in this study.

MATERIALS AND METHODS

Sample population was cancer patients who were admitted in the department of Pediatrics at Kobe University Hospital between January of 2004 and February of 2011. Among them, patients who died by the end of February of 2011 were included in this study. There was no age limit for patients to be treated in our department. Cause of death was no object.

The medical records of the study population were retrospectively reviewed to derive data on age, gender, disease, time since diagnosis, disease status of cancer at death, residential area, actual place of death, preferred place of death of patients and families, and marital status of parents.

2 disease categories were used; hematological disease and solid tumor, brain tumor and non-brain tumor. Time since diagnosis was the period from the initial diagnosis to death. Place of death was categorized into home, hospital, hospice and others. Hospital was additionally classified into Intensive Care Unit (ICU) and non-Intensive Care Unit (non-ICU). The distance between the residential area and Kobe University Hospital was measured using a map published by the Geographical Survey Institute.

Two-sided Fisher's exact test was performed to analyze the association between place of death (home, ICU, non-ICU in the hospital) and those variables. $p < 0.05$ was set as the level of statistical significance. The median age at death and the median distance between our

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hospital and the residence were used to divide study population into 2 groups in order to analyze the association with place of death.

RESULTS

18 deaths of cancer patients were identified. The ratio of male to female was 13 to 5. The median age at death was 12.2 years old (range: 1.3-21.9).

4 patients died at home (22.2%) and 14 patients died in the hospital (77.8%) consisting of 6 ICU deaths and 8 non-ICU deaths. All patients who died in the ICU received aggressive treatments. No death was detected in the hospice and other facilities. Patients' characteristic and place of death are shown in Table I.

Table I. Patients' characteristics and place of death

	number (%)
Gender	
Male	13 (72.2)
Female	5 (27.8)
Median age at death	12.2 years (1.3-21.9)
Place of death	
Home	4 (22.2)
Hospital	14 (77.8)
ICU	6 (33.3)
non-ICU	8 (44.4)
Hospice	0 (0)
Others	0 (0)

6 patients suffered from hematological disease, while 12 patients were affected by solid tumor. 5 patients were in complete remission (CR) and all of them suffered from hematological disease including 4 patients who had received allogeneic hematological stem cell transplantation (HSCT). 13 patients including 1 post-allogeneic HSCT patient were in non-CR.

All home deaths were observed among the patients with solid tumor. All 5 patients in CR died in the ICU under the aggressive treatments for therapy or transplant-related complications.

Home-care service was received by 5 patients. 4 out of 5 patients were cared by home-care service teams until death after they discharged from our hospital. 1 patient using home-care service died in the hospital after the transfer from home because of convulsion.

Preferred place of death was not inquired in any pediatric cancer patient, none of whom was informed about prognosis. As for preference of families, 4 families preferred home deaths, 2 families preferred hospital death, and 1 family delivered the lack of preference. 11 families including 4 parents whose children were in CR were not asked of preference. All patients whose families preferred home deaths died at home. The median distance between our hospital and residence was 28 km. 9 out of 18 patients lived within 28km radius of the hospital. In terms of marital status of parents, 17 out of 18 parents (94.4%) were married.

Univariate analysis on variables relating to disease characteristics showed significance in disease (hematological disease vs. solid tumor; $p=0.010$, brain tumor vs. non-brain tumor; $p=0.023$) and disease status of cancer (CR vs. non-CR; $p=0.0014$). The association between

time since diagnosis and place of death was not significant (0-1 year vs. 2-4 years vs. over 5 years; $p=0.58$). (Table II)

Table II. Disease characteristics and place of death

Disease	Total (n=18) number (%)	Place of death			p value
		Home (n=4)	Hospital (n=14)		
			ICU (n=6)	non-ICU (n=8)	
Hematological disease	6 (33.3)	0	5	1	p=0.010
Solid tumor	12 (66.7)	4	1	7	
Brain tumor	4 (22.2)	3	0	1	p=0.023
Non-brain tumor	14 (77.8)	1	6	7	
Disease status of cancer					
CR	5 (27.8)	0	5	0	p=0.0014
non-CR	13 (72.2)	4	1	8	
Time since diagnosis					
0-1 year	10 (55.6)	2	4	4	p=0.58
2-4 years	6 (33.3)	1	1	4	
Over 5 years	2 (11.1)	1	1	0	

Gender (male vs. female; $p=0.65$), age (aged 12.2 or over vs. less than 12.2; $p=0.44$), distance from the hospital (within vs. beyond 28 km radius of the hospital; $p=0.62$), and marital status (single vs. married; $p=0.22$) showed no significance. Statistical analysis on patients' preference of place of death was not conducted due to the lack of inquiry. The families who were not inquired of preference were excluded from the analysis for preferred place of death of families. Place of death was significantly associated with preference of family (home vs. hospital vs. none; $p=0.029$) (Table III).

Alternative analyses for the distance from residence (within and beyond 10 km radius of the hospital) were conducted, which showed no significance ($p=0.57$), either (Not shown).

As a result, factors influencing place of death were disease (hematological disease, solid tumor, and brain tumor, non-brain tumor), disease status (CR, non-CR), and preference of place of death of patients' families.

DISCUSSION

This is the first English publication on place of death of pediatric cancer patients in Japan. Despite the small sample size, some features were identified in this study.

The first is the low percentage of home death. Home death is 22.2% and the majority of pediatric cancer patients died in the hospital. One possibility for the high proportion of hospital death may be the attachment to hospitals in addition to the anxiety about leaving a familiar environment. The main facility to treat pediatric cancer patients is a hospital in Japan. Patients and families spend a long period in hospital and may feel comfortable in rapport with medical staff. They may become reluctant to be cared at home at a prospect of difficulties such as establishing communication with community healthcare team. Another reason may be under-developed home care service and hospice for pediatric patients. In Japan, primary care physicians generally do not see children due to the lack of medical

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training for pediatric patients which is caused by Japanese medical training system. Therefore, it is difficult to find a home doctor who cares pediatric cancer patients. One of 4 patients who died at home was an adolescent for whom a home doctor is relatively available. Remaining 3 patients died at home in the later term of this study period when a regional medical liaison office opened in our hospital. Since then, information of regional home care service was easily available through that office, which might result in ease of finding home doctors. Organized home care service and its information may lead to increased home deaths of children in the future.

Table III. Other variables and place of death

	Total (n=18) number (%)	Place of death			p value
		Home (n=4)	Hospital (n=14)		
			ICU (n=6)	non-ICU (n=8)	
Gender					
Male	13 (72.2)	2	5	6	p=0.65
Female	5 (27.8)	2	1	2	
Age					
0-12.2 years old	9 (50.0)	3	2	4	p=0.44
Over 12.2 years old	9 (50.0)	1	4	4	
Preference (patient)					
Home	0 (0)	0	0	0	n.a.
Hospital	0 (0)	0	0	0	
None	0 (0)	0	0	0	
Not Inquired	18 (100)	4	6	8	
Preference (family)					
Home	4 (22.2)	4	0	0	p=0.029
Hospital	2 (11.1)	0	0	2	
None	1 (5.6)	0	0	1	
Not Inquired	11 (61.1)	0	6	5	
Distance from residence					
0-28 km	9 (50.0)	3	3	3	p=0.62
Over 28km	9 (50.0)	1	3	5	
Marital status of parents					
Single	1 (5.6)	1	0	0	p=0.22
Married	17 (94.4)	3	6	8	

n.a.: not available

The lack of hospice death is understandable as no hospice for pediatric cancer patients exists in Japan. It is currently under-construction. To raise awareness and promote usage of hospice, its development and training program on pediatric palliative care will be required.

The percentage of ICU deaths (33.3%) seems relatively high compared to the study conducted by Klopfenstein et al(7). Place of death is associated with multidimensional factors such as ethnicity(4), therefore, it is hard to state it assertively. Most patients who died

in the ICU were affected by complications related to HSCT and it may reflect the increase of feasibility of HSCT because of advanced medical technology such as non-myeloablative SCT and introduction of cord blood as stem cell source.

The second feature is the detection of factors which influence place of death of pediatric cancer patients. Disease (hematological disease vs. solid tumor, brain tumor vs. non-brain tumor), disease status (CR vs. non-CR) and preference of family had significant association with place of death. In the previous study which targeted children, older age, lower socioeconomic status, and non-hematological disease(2) are influential factors. Preference of family also influences place of death of adults with cancer as well as preference of patient(5). However, preference of place of death is not necessarily congruent between patients and their families(13). Preference of place of death of caregivers is shaped by multiple factors such as experience of service, informal care resources(14), quality of service and good death concepts(11). Appropriate place of death should be considered carefully in case of the lack of patients' preference.

Brain tumor, one of solid tumors, has been reported to be less associated with home care among pediatric patients(12), probably because it requires multidimensional supportive care(9). Zelcer et al. reported that the barriers to home deaths in pediatric patients with CNS tumor are symptom control, financial and practical difficulties, and in appropriate community supports(15). Home death of patients with brain tumor may increase by solutions to these issues. The reason for significant association between brain tumor and home deaths is unspecified. In Japan, physicians except for pediatricians and pediatric surgeon do not commonly see children. The exception is neurosurgeons. Pediatric patients with brain tumor had been treated by neurosurgeons who operated and gave chemotherapy. Home doctors who expertise neurosurgery may actively accept children with brain tumor based on their medical experiences.

It is highly imaginable that disease status influences place of death. Cancer patients in CR, their families and staff aim cure of disease and complications and reluctantly abandon the treatments including intensive care. The study which targets pediatric cancer patients in non-CR would result in different outcomes. Study criteria to include cancer patients with CR may lead to decreased inquiry of preferred place of death of patients and their families.

Socioeconomic status is one of the factors influencing place of death in the previous reports. In this study, marital status, which showed no significant association with place of death, is the only variable concerning socioeconomic status. Variables such as education and income, which are reported to be factors influencing place of death, are not analyzed in this study due to the lack of data. Variety in socioeconomic status is harboring in Japan as well as other countries, therefore, more variables concerning socioeconomic status should be included in the next study.

The third feature is that all preference of family were congruent with actual place of death. The disparity between actual and preferred place of death may influence physical and mental health of bereaved family, which may induce deteriorated quality of life(10). Reduction of the disparity is required to improve quality of life for patients as well as their families.

The lack of inquiry about preferred place of death of patients was revealed in this study. The lack of information about prognosis to pediatric patients might discourage direct inquiry. Considering Japanese composition to keep feelings insides and the fact that death is considered as taboo to talk, staff might hesitate to inquire preferred place of death of their family as well. Preference of family may not reflect patient's preference. Currently, truth telling to pediatric patients is encouraged for patient's better comprehension of disease status,

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stepping out of Japanese tradition. It may lead to active inquiry of preference of pediatric cancer patients and actual place of death may be changed in the future.

The study on place of death in pediatric patients is few in the world. It may be due to the complex of conducting the study of pediatric cancer patients. Immaturity due to the young age and the lack of telling truth to patients themselves may interfere in the choice of place of death, resulting in the weakness of the study. Moreover, the health care system that provides sufficient protection for children in Japan may lead to less interest in increased health care cost and the study on place of death.

Near homogeneity in terms of people, religion, culture and socioeconomic status in Japan is a different context from western countries that frequently conduct the studies on place of death. This study may emphasize the homogeneous context of place of death such as the reduced variation of therapeutic strategies as it was conducted in a single institute. This may be the strength of this study. The limitation is a small study population. Collaborate on research activities may clarify the reality and elucidate characteristics of place of death of pediatric cancer patients in Japan more clearly so that it will lead to improved quality at the end-of-life of pediatric cancer patients.

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