Home Care for End-of-Life AYA Cancer Patients

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Backgrounds

Home medical care spreads in Japan from a patient’s and family member’s hope to undergo medical treatment in one’s home. It is tendency to increase with approximately 8% of cancer death at home (2011). In general, patients in adolescent and young adult (AYA) generation are rare compared to senior adults and elderly.

Objectives

- 1. Clarify the situation of at-home doctor treating AYA patients with cancer
- 2. Clarify at-home doctors feeling difficulties in medical treatment of AYA patients with cancer

Methods

In this exploratory study, we provided a questionnaire to physicians in home care clinics. Eligibility criteria: 1. patients made a request of home care adjustment to the National Cancer Center Hospital consultation support center by October, 2017 from December, 2013. 2. the choice of the at-home medicine was carried out, and the first visit was carried out after a discharge.

Results

Figure 1. Study flow diagram

Table 1. Demography of homecare physicians

No. of respondents	36
Age(y)	50.2 (34-70)
Male/Female	5/31
Year in practice(y)	23.1 (10-45)
Year in homecare (y)	19.1 (1-45)
Year in palliative medicine (y)	11.4 (1-28)

Table 2. Home care situation from questionnaire

Home care situation from questionnaire	
Total no. of patients (per one doctor)	2577 (71.6)
Total no. of died patients (per one doctor)	1392 (38.6)
Total no. of AYA patients with cancer (per one doctor)	52 (1.4)
Total no. of died AYA patients with cancer (per one doctor)	27 (0.75)
Treatment and care for 52 AYA patients with cancer	
Pain management (opioid)	50 (96%)
Sedation	16 (31%)
Oxygen	26 (50%)
Thoratic and abdominal drainage	9 (17%)
Blood transfusion	2 (4%)
Antibiotics	7 (13%)
Decubitus care	2 (4%)
Delusion control	10 (19%)

Table 3. Difficulties regarding management of symptoms and other problems

	Patients having this problem	Doctors feeling difficulties to control this
Physical problems		
pain	23	10(43%)
breathlessness	19	9(47%)
nausea and vomiting	15	9(60%)
fatigue	23	12(52%)
edema	10	5(50%)
pleural effusion/ascites	10	6(60%)
decubitus	4	1(25%)
Mental problems		
delirium	9	5(56%)
depression	11	6(55%)
congenital impairment	2	2(100%)
anxious	22	14(64%)
Social problems		
problem of working or going to school	9	4(44%)
financial problem	16	12(75%)
caregiver burden	19	13(68%)
marriage and relationship to spouse/partner	4	3(75%)
problem about parents	9	7(78%)
problem about partners	10	7(70%)
problem about children	10	8(80%)
fertility	3	3(100%)
Spiritual problem and advance care planning		
spiritual pain	15	10(67%)
truth telling (disease) to the patient	10	4(40%)
truth telling (life expectancy) to the patient	14	10(71%)
advance care planning	14	9(64%)
advance directives	11	9(82%)
truth telling (disease) to caregivers	9	4(44%)
truth telling (life expectancy) to caregivers	14	8(57%)
advance care planning with caregivers as a surrogate	12	7(58%)
advance directives with caregivers as a surrogate	9	7(78%)
caregivers’ acceptance	18	13(72%)

Figure 2. General perspectives on difficulties in the end of life homecare for AYA cancer patients

Discussions

- The number of cancer cases in Japan in 2013 was 862245 at all ages, of which 20,259 in the AYA generation and 2.3% of the total population. Our data are almost consistent with this.
- The number of AYA generation cancer patients visited by 36 respondents in the last year is very small, with 52 people on average, and one home doctor visits 1.4 a year on average, and 11 people It is considered that there is little experience due to its rarity, saying that they have not visited in a year.
- It turned out that at-home physicians have felt difficulties for physical pain, mental pain, social problems, and spiritual problems in the medical care of AYA cancer patients.
- It will be useful information by comparing with the home medical care of the adults. It would be even more useful if we could analyze the patient's family's feeling of satisfaction and feeling.