論　文

滋賀県における在宅ホスピスケアの実態
－開業医のアンケート調査から－

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背景　終末期癌患者の死亡場所としてはいまだに病院施設が多く、緩和ケア・ホスピス病棟における死亡率は約4％にすぎない。また、癌患者が残された時間を有意義に過ごすためには、在宅で死を看取るのが最も適切なケアであるといわれているが、「最期は家で過ごしたい」という患者や家族の希望を叶えるためには、家庭（在宅）での疼痛管理や死の看取りを視野に入れた在宅ホスピスケアシステムの整備が必要である。また、このケアシステム構築のためには、実際の診療に携わる医師の考え方や、病院との連携などの問題点や課題を明らかにする必要がある。

目的　高齢化率17.3％である滋賀県において、在宅ホスピスケアの実態を明らかにする。すなわち、在宅ホスピスケアを実施していく上で、中心的な役割を担う開業医のアンケート調査を実施し、地域における在宅ホスピスケア構築のための問題点と課題を検討する。

方法　滋賀県下772名の開業医に対して、在宅ホスピスケアに関する質問紙を留め置き法により実施した。

結果　在宅ホスピスケアを実施している開業医は294名中75名(25.5%)であった。しかし、実施していない開業医219名の内、在宅ホスピスケアの必要性については116名(53.0%)がその必要性を認めていた。

在宅ホスピスケアを実施している医師は平均1.9名の患者を受け持っており、患者の殆どはその家族や病院からの依頼によるものであった。医師の患者対応の方法は大部分が往診であり、その内容は、補液や疼痛緩和、緊急時の対応などであった。また、医師は患者の緊急事態に備えて緊急時の連絡方法を整備していた。しかしその一方で、患者に対して24時間対応ができない、患者対応のために肉体的・精神的負担が大きすぎるなどの指摘があった。

在宅ホスピスケアを実現するためには、医師の条件のみならず、患者や家族の在宅ホスピスケアに対する強い要望があること、患者を実際に介護する人材のあることなどであり、さらに、病院と地元医師会、開業医間の連携が必要と考えていた。またその一方で、病院の緩和ケア病棟や訪問看護部門が中心的役割を担うことを希望する医師も存在し、地域に緩和ケア病棟やホスピスの整備が少ないことも在宅ホスピスケアを困難にする一因と考えていた。

結論　在宅ホスピスケア構築のためには、患者の急変時に直ちに患者を受け入れられる基幹病院の存在、医療従事者の教育・研修を行う教育機関の充実、在宅ホスピスケアを統合する実施機関の整備、開業医と連携する緩和ケア病棟ならびにホスピスの設置などが必要と考えられる。

キーワード：在宅ホスピスケア、開業医、末期癌患者

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I Introduction

The report of NHPCO (National Hospice and Palliative Care Organization), 2003, states that there are 3, 200 institutions carrying out hospice program in the United States so as to suppress skyrocketing medical expenses. Approximately 885,000 patients use such facilities. According to death records in the U.S., more than one quarter of the 2,400,000 deaths recorded receive hospice care.

The advantages of hospice home care are to keep down medical expenses and heal the pain of a family that has nursed their loved one until the end of his/her life. A report[1] indicates that a bereaved family feels almost no regret over using hospice home care. Yet despite of the advantages, hospice home care is not as popular as it should be. The biggest reason is the physical and emotional pressure experienced by doctors and nurses in a hospice team who take care of terminally ill patients. In carrying out hospice home care, it is required for a team of home doctors and nurses not only to provide medical care for a dying patient, but also to help him/her to be prepared for the coming death ; visit the patient's home just before death; deal with the postmortem treatment; and provide companionship and consultations with the bereaved family.

Whereas doctors who carry out home hospice care are required to have suitable knowledge, it is more important for nurses to be trained to deal with a variety of emergency situations and to be able to make proper judgments when providing emotional care to dying patients and their families.

Financial problems and shortages of experts are cited as reasons for the troubled implementation of the system. Big gaps in the medical environment and system between larger cities where populations are concentrated and rural areas where depopulation and the aging process of the population is accelerated, and the added pressure on home doctors and nurses, as well as the delayed spread of the information and the low degree of recognition are all affecting the promotion of home hospice care.

Although cooperation on the part of local general practitioners is essential for the establishment of home hospice care service, surveys of doctors on their attitude towards hospice care and the current situation has so far barely been conducted. As to the entire Shiga Prefecture, no survey result of this nature exists.

In Shiga Prefecture, where the percentage of the aging population comprises 17.3%[2], and the process of aging is advancing, with the aim to establish hospice home care service, we have carried out the first survey which covers all nine local medical associations. The questionnaire was answered by home doctors who take care of terminally ill patients and the family and general practitioners who are the pillar of local medical services. We believe that this survey is able to clarify the actual situation, problems and obstacles when it comes to the practice of hospice home care service in Shiga Prefecture.

II Definition of the terminology

With the reference to the fundamental principle of hospice home care services established by the Home Hospice Association[3] , in this survey we defined hospice home care service as being a system whereby care for the dying is practiced in the home so that terminally ill patients (cancer patients) can be released from physical, emotional, social, and spiritual pains and live both mentally and physically at ease while maintaining the dignity as a human being till the end of their life. The fundamental principle of the Home Hospice Association indicates that a home should be a place where a dying patient and their family can be relaxed most and their intentions can be exercised most. Therefore, hospice home care is also considered to be a care system to provide the necessary aid for a dying patient and their family to fulfill their wish to spend the rest of their life at home.

III The purpose of the research

Through clarification of the current hospice home care situation in the region, this research will study the problems and issues the implementation of home hospice care is faced with in order to provide data for the future establishment of the system.

Ⅳ The subjects and method of the survey

The subjects of the survey were 772 general practitioners who were registered with the Medical Association of Shiga Prefecture as of June 2002. The purpose and contents of the questionnaire were first explained to the chairmen of nine local medical associations and also at each respective board of directors meeting to obtain their assistance in the survey, and then with their consent, practitioners from the each association were notified of the upcoming survey.

The survey was carried out from July to August of 2003. The questionnaire was mailed to each practitioner and they were requested to mail it back after having kept it for two weeks.

The contents of the questionnaire covered the background of each facility such as the numbers of years of practice, beds, and staff, an occupational category, the name of medical association he/she belongs to, whether there is an adjoining facility to conduct visiting nursing service in his practice. It also asked whether or not they are interested in hospice home care and how much they understand the service. In the case of a practitioner who has conducted hospice home care service, the motivation, the number of patients, specific medical services, other services, and obstacles were also asked. In the case of a practitioner who has never carried out the service, the reasons were he/she was asked to tick applicable reasons in the questionnaire and also describe details in his/her own words. In addition, free description of opinions were sought regarding the necessary requirements and the important factors to conduct the service, the organizations they think should play a central role in implementation and expansion, and the reason for the difficulty in actual implementation in Shiga Prefecture, as well as any other suggestions.

Ⅴ Ethical considerations

In carrying out the survey, the following points were clarified in writing: The information gathered would only be used for this research and would not be used for any other purposes. The data was anonymous and handled by number. No answer for the questionnaire should be forcibly made. No disadvantage would be caused due to the survey.

Ⅵ The results of the survey.

Of the 772 practitioners 297 or 38.5% responded. The percentages of the 9 medical areas were: 37.7% from Otsu-City, 32.8% from Kusatsu-Ritto area, 35.8% from Moriyama City-Yasu County, 38.2% from Koga-County, 45.5% from Omihachiman City-Gamou County, 50.0% from Yokaichi-City, 52.4% from Hikone, 38.1% from Kohoku-area, and 37.9% from Takashima-County. These figures show , we were able to receive almost the same number of respondents around the entire Shiga Prefecture. Among them, 294 answers were taken as valid with the exclusions of three doctors whose affiliation to local medical associations were unclear (the percentage of valid answers was 38.1%).

1. Background of facilities

1) When they started hospice care

Of the respondents, 108 facilities, which comprises the largest part, were set up from 1990-99 (36.7%), followed by 60 facilities which were established from 1980-89 (20.4%), and then 52 facilities which were opened before 1969 (17.7%) (Table1).
However, the ratio of the establishment before 1969 is shown to be higher by some medical associations; 35.5% in Kohoku medical association (ranked the first in the Kohoku region), 25% in Koga County medical association, 34.1% in Hikone medical association, 27.3% in Takashima-County medical association (ranked the second in each respective region).

2) The type of the job and number of the staff in the facilities

The record shows the total number of 284 full-time and 53 part-time doctors with some exception of no number of doctors mentioned. On average, the number of doctors was one full time and 0.2 part time per facility. The number of nurses was 146 full time, 104 part-time, 87 full-time practical nurses, and 53 part-time practical in total. On average 0.5 full-time and 0.4 part-time nurses, and 0.3 full-time and 0.2 part time practical nurses work per facility. As additional staff, physical therapists, occupational

Table 1 The opening year

		A number of samples	Before 1969	1970-79	1980-89	1990-99	2000 onwards	N. A.
The total		294	52 (17.7%)	29 (9.9%)	60 (20.4%)	108 (36.7%)	33 (11.2%)	12 (4.1%)
The Area of each medical association a doctor is registered with	Otsu-City	88	12 (13.6%)	7 (8.0%)	25 (28.4%)	31 (35.2%)	10 (11.4%)	3 (3.4%)
	Kusatsu/ Ritto	35	1 (2.9%)	3 (8.6%)	5 (14.3%)	21 (60.0%)	5 (14.3%)	0 (0.0%)
	Moriyama City/ Yasu County	24	1 (4.2%)	2 (8.3%)	3 (12.5%)	13 (54.2%)	5 (20.8%)	0 (0.0%)
	Koga-County	20	5 (25.0%)	3 (15.0%)	2 (10.0%)	6 (30.0%)	4 (20.0%)	0 (0.0%)
	Ohmihachiman City/ Gamo County	23	2 (8.7%)	4 (17.4%)	10 (43.5%)	6 (26.1%)	1 (4.3%)	0 (0.0%)
	Yokaichi-City	15	2 (13.3%)	1 (6.7%)	4 (26.7%)	6 (40.0%)	1 (6.7%)	1 (6.7%)
	Hikone	44	15 (34.1%)	6 (13.6%)	7 (15.9%)	11 (25.0%)	2 (4.5%)	3 (6.8%)
	Kohoku	31	11 (35.5%)	3 (9.7%)	3 (9.7%)	7 (22.6%)	3 (9.7%)	4 (12.9%)
	Takashima-County	11	3 (27.3%)	0 (0.0%)	0 (0.0%)	6 (54.5%)	2 (18.2%)	0 (0.0%)

therapists and social workers were cited to be working for some facilities, and volunteer workers were marginally accepted.

3) The number of hospice care facility that provides home care service.

Thirty-seven facilities had a related facility that provides hospice home care (12.6%) whereas 243 facilities did not have it (82.6%) (Figure 1). Among them, in the Kohoku region (n=31), 9 facilities (29.0%) carried out hospice home care.

2. Recognition and understanding towards hospice home care

For the question as to whether or not they have ever heard of "Hospice home care", 247 doctors answered Yes(84.0%), and 46 doctors No(15.7%) (Figure 2).

On the other hand, the recognition of the existing

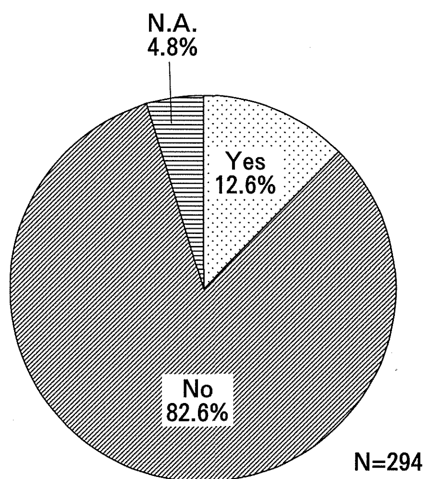

figure1
Hospice related facilities providing home care service

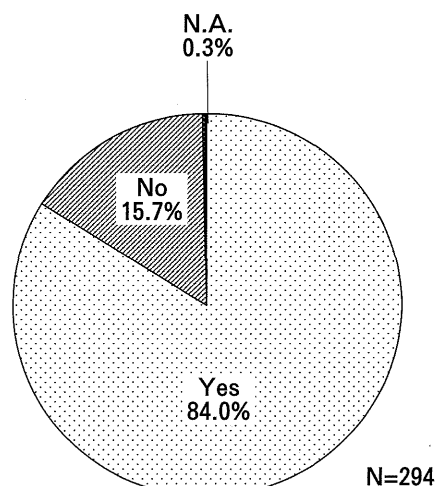

figure2
Recognition towards hospice home care

Table2 Recognition to hospice home care

		A number of samples	Have you ever heard about hospice home care ?					
			YES		NO		N.A.	
The total		294	247	(84.0%)	46	(15.7%)	1	(0.3%)
The opening year	Before 1969	52	48	(92.3%)	3	(5.8%)	1	(1.9%)
	1970-79	29	26	(89.7%)	3	(10.3%)	0	(0.0%)
	1980-89	60	46	(76.7%)	14	(23.3%)	0	(0.0%)
	1990-89	108	89	(82.4%)	19	(17.6%)	0	(0.0%)
	2000 onwards	33	26	(78.8%)	7	(21.2%)	0	(0.0%)
An area of medical associations a doctor is registered with	Otsu-City	88	72	(81.8%)	16	(18.2%)	0	(0.0%)
	Kusatsu/Ritto	35	29	(82.9%)	6	(17.1%)	0	(0.0%)
	Moriyama City/Yasu County	24	21	(87.5%)	3	(12.5%)	0	(0.0%)
	Koga-County	20	15	(75.0%)	5	(25.0%)	0	(0.0%)
	Ohmihachiman City/Gamo County	23	21	(91.3%)	2	(8.7%)	0	(0.0%)
	Yokaichi-City	15	13	(86.7%)	2	(13.3%)	0	(0.0%)
	Hikone	44	39	(88.6%)	4	(9.1%)	1	(2.3%)
	Kohoku	31	27	(87.1%)	4	(12.9%)	0	(0.0%)
	Takashima-County	11	9	(81.8%)	2	(18.2%)	0	(0.0%)

The name of towns, cities and counties are taken from a list of medical association in Shiga prefecure .
In June, 2002 (The name of county and cities was changed in 2003, so how can I explain it?)

facility varies by the year of their commencing of the service. 92.3% doctors answered "yes" when their service started before 1969, and the recognition level is slightly lower among doctors whose facilities started the service after 2000 and 78.8% doctors answered "yes."

The rate of recognition by each medical association base showed that in Ohmihachiman City-Gamo County, 91.3% doctors knew of the service, and on the contrary, in Koga-County, only 75.0% doctors knew the service (Table 2).

3. Interests towards home hospice care

Of the respondents, 136 doctors showed their interest in the service (46.2%), and 47 doctors did not show any interest in the service (16.0%). Then, 109 doctors were unclear about their position of interest in the service (Figure 3). When combining the doctors who showed no interests with doctors who were not sure, about the half of the doctors (53.1%) showed no interest in the service. Compared with other medical associations, those doctors who belong to the medical associations which are located in the area where public hospitals are offering hospice and palliative care in their adjoining units, showed less interest in

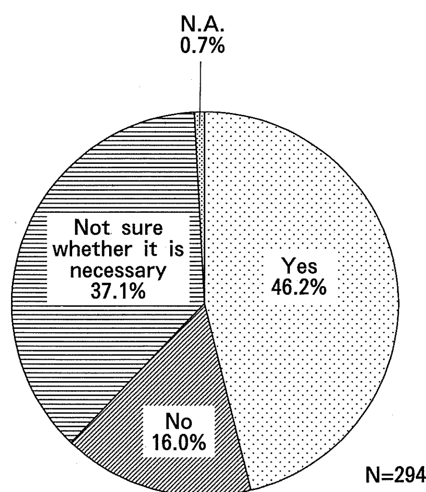

figure3
Interest in hospice home car

Table 3 Interest in hospice home care

		A number of samples	Are you ever interested in hospice home care? YES		NO		Not sure whether being interested or not		N.A.	
	The total	294	136	(46.2%)	47	(16.0%)	109	(37.1%)	2	(0.7%)
An area of medical associations a doctor is registered with	Otsu-City	88	37	(42.0%)	11	(12.5%)	39	(44.3%)	1	(1.1%)
	Kusatsu/Ritto	35	11	(31.4%)	12	(34.3%)	12	(34.3%)	0	(0.0%)
	Moriyama City/ Yasu County	24	9	(37.5%)	4	(16.7%)	11	(45.8%)	0	(0.0%)
	Koga-County	20	7	(35.0%)	5	(25.0%)	8	(40.0%)	0	(0.0%)
	OhmihachimanCity/Gamo County	23	12	(52.2%)	4	(17.4%)	7	(30.4%)	0	(0.0%)
	Yokaichi-City	15	14	(93.3%)	1	(6.7%)	0	(0.0%)	0	(0.0%)
	Hikone	44	22	(50.0%)	5	(11.4%)	17	(38.6%)	0	(0.0%)
	Kohoku	31	18	(58.1%)	2	(6.5%)	11	(35.5%)	0	(0.0%)
	Takashima-County	11	5	(45.5%)	2	(18.2%)	3	(27.3%)	1	(9.1%)

hospice home care as follows: Hikone (50.0%), Moriyama City-Yasu County (37.5%), Otsu-City (42.0%) (Table 3).

4. Reality of hospice home care

Seventy-five doctors provide hospice home care (25.5%), and 219 doctors have never done so (74.5%); therefore, only one quarter of the total number of doctors cater to the service (Figure 4).

Among the doctors who provide hospice home care, 63 doctors specialize mainly in internal department (84.0%), and only 12 doctors specialize other department (16.0%), such as 4 doctors surgery, 4 doctors pediatrics, 1 orthopedics, 1 anesthesiology, and 2 are unknown.

Based on the data above the actual implementation of hospice home care and the degree of interest in hospice home care were compared using χ^2 test, showing a significance difference at $p<0.01$. Analyzing he data by the year of establishment, it was found that only 12.1% facilities provide hospice home care among those who commenced the service after 2000. The reasons, which were listed in the form of free description can be summarized as "Under the present circumstances, the structure of the service has yet to be prepared." In the Kusatsu-Ritto region, its low ratio of provision(11.4%) can be explained by

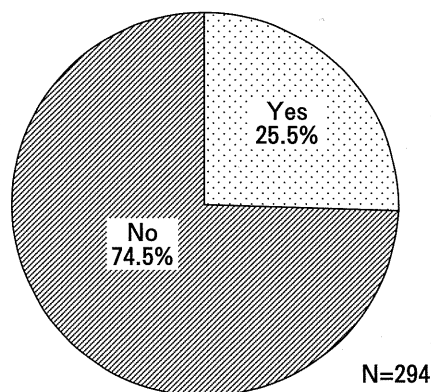

figure4
Practice of hospice home care

Table 4 Practice of hospice home care

		A number of samples	Never practiced before ? YES		Never Practiced before	
	The total	294	75	(25.5%)	219	(74.5%)
The opening year	Before 1969	52	14	(26.9%)	38	(73.1%)
	1970-79	29	7	(24.1%)	22	(75.9%)
	1980-89	60	10	(16.7%)	50	(83.3%)
	1990-99	108	34	(31.5%)	74	(68.5%)
	2000 onwards	33	4	(12.1%)	29	(87.9%)
An area of medical associations a doctor is registered with	Otsu-City	88	24	(27.3%)	64	(72.7%)
	Kusatsu/Ritto	35	4	(11.4%)	31	(88.6%)
	Moriyama City/ Yasu County	24	5	(20.8%)	19	(79.2%)
	Koga-County	20	5	(25.0%)	15	(75.0%)
	OhmihachimanCity/ Gamo County	23	6	(26.1%)	17	(73.9%)
	Yokaichi-City	15	4	(26.7%)	11	(73.3%)
	Hikone	44	9	(20.5%)	35	(79.5%)
	Kohoku	31	15	(48.4%)	16	(51.6%)
	Takashima-County	11	3	(27.3%)	8	(72.7%)

the following: relatively new service commencing years; 60% between 1990 and 99, and 14.3% after year 2000, and the population increase with a low ratio of aging population 11-13% (Table 4). On the contrary, in the facilities that belong to Kohoku medical association, 48.4% of facilities provide hospice home care; the reasons are cited as follows: The lack of main hospitals put them in a position not to be able to decline the requests. Home hospice care is positioned within the scope of their home medical care.

1) About the facilities providing hospice home care (n=75)

(1) Achievement in the past one year

In the past one year, 11 facilities provided hospice home care for more than five terminal cancer patients (14.7%: one facility provided the service for 13 patients). Three facilities provided the service for four terminal cancer patients (4.0%), seven facilities for 3 patients (9.3%), and each 15 facilities respectively for two and for one patients (20.0%). Twenty-one facilities provided for none (28.0%) and the answers from the rest three facilities were not available. On average 1.9 terminal cancer patients per one facility were provided with hospice home care. On the other hand, except for cancer patients, 11 facilities provided hospice home care service for more than five other terminally ill patients (14.7%: One facility provided service for fourteen patients, and another for 20 patients). Four facilities provided the service for four patients (5.3%), 6 facilities for 3 patients (8.0%), 11 facilities for 2 patients (14.7%), 17 facilities for none and 4 facilities with no answer. On average one facility provided the service for 2.3 terminally ill patients.

The numbers of medical staff who had experience in providing hospice care were as follows: zero in 22 facilities (29.3%), one in 19 facilities (25.4%), two in 10 facilities (13.4%) and three or more in 13 facilities (17.2%). Among them was one facility where 10 staff members had such experience. No data were obtained from eleven facilities. On average, merely 1.3 medical staff per facility had the experience.

(2) The reason why they started hospice home care

The result of plural answer survey shows 63 started because of requests from a patient's family (84.0%), and 38 from a hospital (50.7%), and 26 from a patient himself (34.7%), and there were only a few requests from practitioners or local administration such as the social welfare office (Figure 5).

(3) Concrete contents of the service

The result of plural answer survey shows that many of services provided were medical treatment. The house call ranked the first with 73 (97.3%), followed by intravenous transfusion with 56 (74.4%). Forty-nine said it is mainly palliative pain control (65.3%), and 48 answered emergency treatment (64.0%). Others are; 33 provide pressure ulcer's treatment (44.0%), 27 cater to home oxygen therapy (36.0%), 22 provide tube feeding (29.3%), and only 11 people provided nursing care such as sanitation and cleaning body (14.7%) (Figure 6).

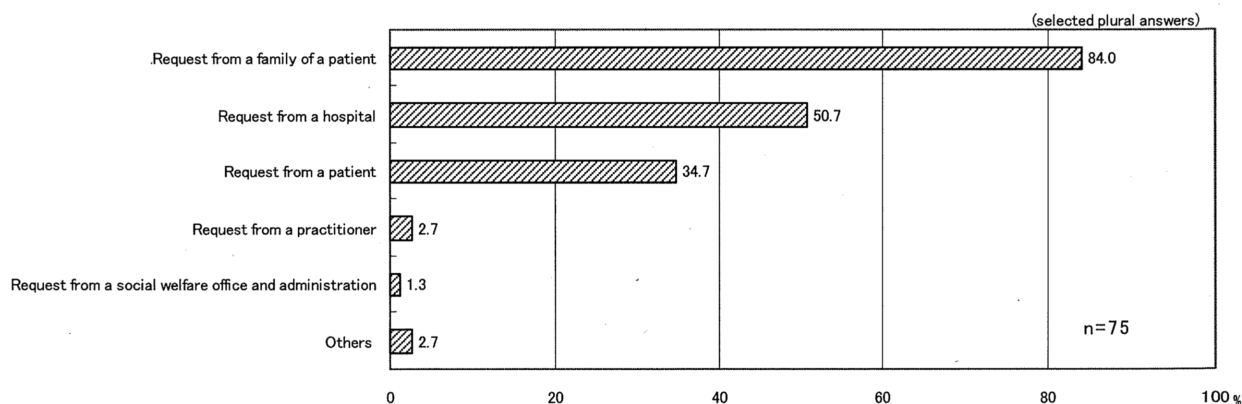

figure5 The reason for starting hospice home care

(4) Strategy and structure in providing hospice home care

From the result of plural answers, 66 answered that they made themselves reachable anytime for the patients' needs (88.0%), 61 travel out to a patient's home even on holiday or during night when requested (81.3%), 25 had 24 hours around-the-clock system (33.3%) (Figure 7).

(5) Hardships in order to provide hospice home care service

The participants of the survey were asked to choose two suitable answers. Thirty-five of them point out physical exhaustion (46.7%), 35 of them answers that they cannot set up 24 hours service. Both of them ranked the first, followed by 28 who claimed psychological pain (37.3%), and then 16 complained a shortage of the team and the staff (21.3%), 13 cited the lack of mutual understanding between the team of medical staff, and a patient and the family (17.3%), and 12 the lack of mutual understanding between a patient and the family (16.0%). Other opinions are; 5 of them found it difficult to look for emergency hospital when necessary (6.7%), 4 of them said a patient's family is not attentive and does not give any assistance (5.3%) (Figure 8).

(6) Essential condition in order to provide hospice home care

In providing hospice home care, the participants were

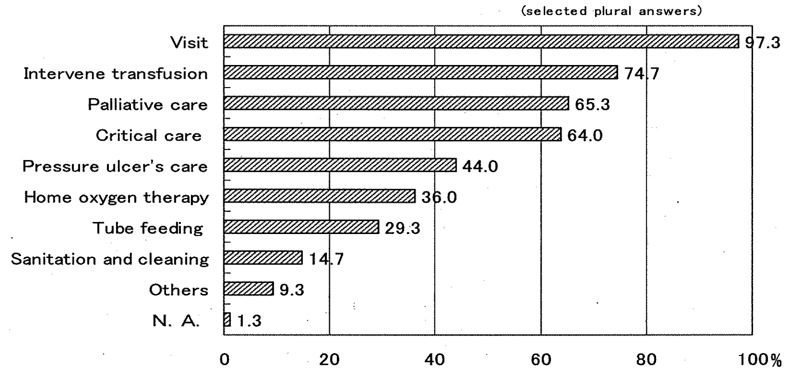

figure6 Concrete contents of hospice home care service

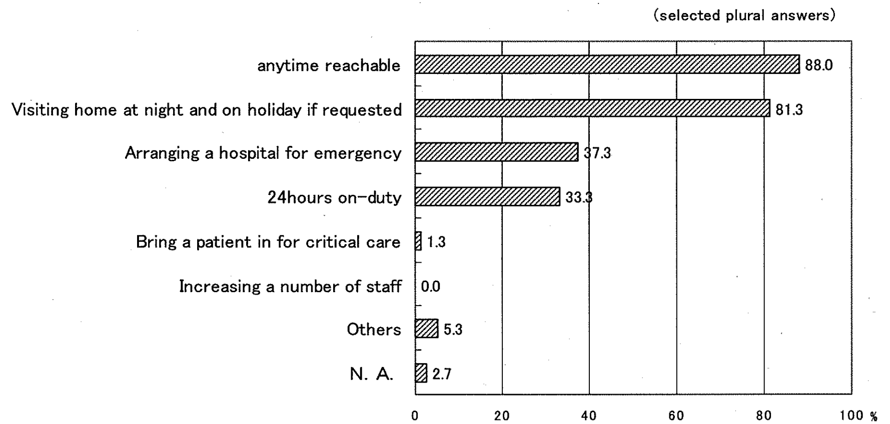

figure7 Treatment when providing hospice home care

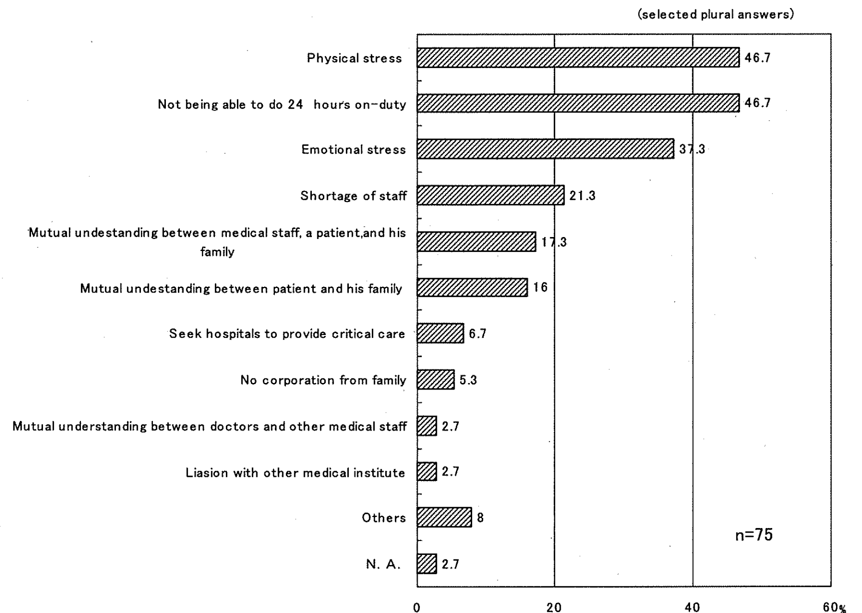

figure8 Difficulties in providing hospice home care

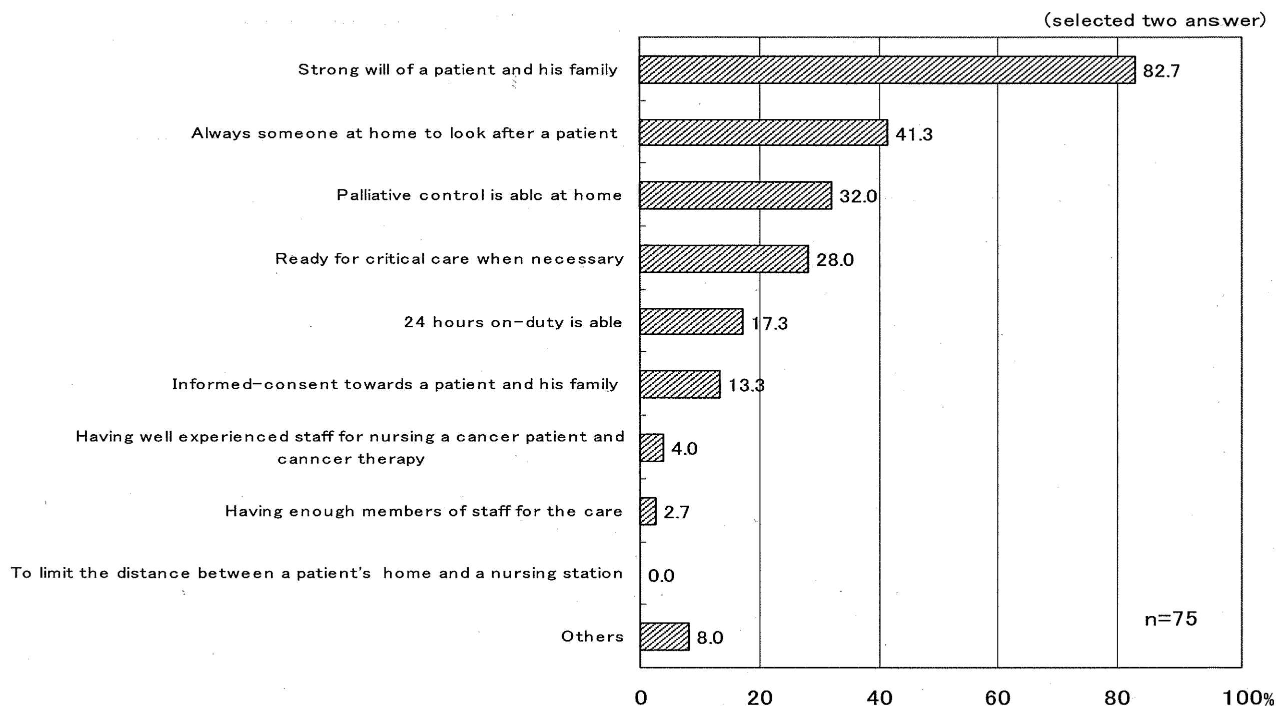

figure9 Essential condition to provide hospice home care

asked to choose two suitable answers. Sixty-two of them chose the answer that a patient and his family must have a strong will to spend the rest of life and to die at home (82.7%). Thirty-one of them chose a condition that someone always has to look after a patient at home (41.3%), 24 of them point out that palliative control can be actualized at home (32.0%). In the survey, 10 of the respondents (13.3%) considered that informed consent should be obtained, 3(4.0%) considered that medical staff are required to have experience in treating and nursing cancer patients, indicating that these factors are not essential (Figure 9).

2) Facilities that do not provide hospice home care service (n=219)

(1) The reason they do not provide hospice home care

Of the 219 respondents, 106 participants of the survey answered that no one has requested the service (48.4%), 102 of them considered that it is difficult to provide the service due to shortage of staff and burden the team of the medical staff have to shoulder (46.6%), 27 answered there was no request from hospitals (12.3%) and 20 of them pointed out that they do not have expert nurses who have provided home care service towards cancer patients (9.1%) (Figure 10).

Six participants answered that they are unable to embark on it, as they have just established the unit (2.7%), and most of them are located in the facilities in Moriyama City-Yasu County area with 5 facilities opened after 2000. Another one established between 1990-99. Other 50 participants (22.8%) gave the reason as follows; 23 of them are not specialized in hospice and palliative care (46.0%), 5 of them are too old to provide the service (10.0%), 6 of them cited systematical impediments such as the lack of medical license to handle narcotics (12.0%). Three of them said that they had provided the service, but never thought that it was hospice home care, they just had done what they could do (6.0%).

(2) Needs to provide hospice home care

To the question that whether hospice home care is necessary in the future, 116 of them are positive (53.0%), 27 of them are negative (12.3%) and 73 of them

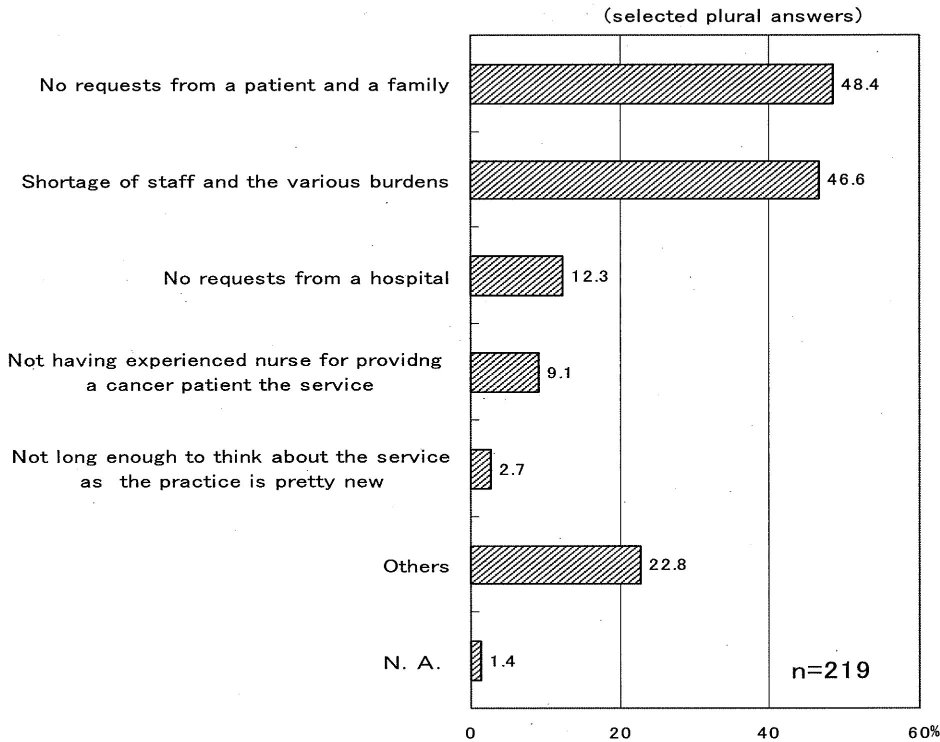

figure10 The reasons of not carrying out hospice home care

are not sure (33.3%) (Figure 11).
Among 27 participants who consider the service not necessary, 17 of them said that they are not specialized in the hospice and palliative care as a doctor and they do not have a patient willing to receive the service (63.0%), 3 of them consider that it will be only established with understanding and strong will of a patient and his family (11.1%), and then, 2 of them are too old to provide the service (7.4%).

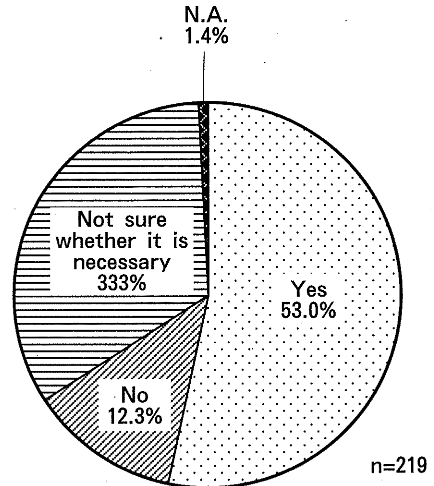

figure11
Whether hospice home care is necessary

5. Preparation to carry out hospice home care (N=294)

To the question, what kind of preparation has to be done to provide hospice home care. The respondents were allowed to choose two of the answers. Of the 294 respondents, 158 people pointed out that it is important to set up a close linkage among doctors such as hospitals, practitioners, local medical association (53.7%), 139 of them considered social welfare should be more improved so that the physical and financial burden of home care would be reduced (47.3%), 83 of them considered that through increasing the number of hospice units, and the units should also be a driving force to provide hospice home care (28.2%), 71 of them considered that the number and the quality of a home care station should be increased (24.1%), 35 of them believed that promoting informed consent and inspiring patient's mind are the top priority (11.9%) and 34 of them thought that it is

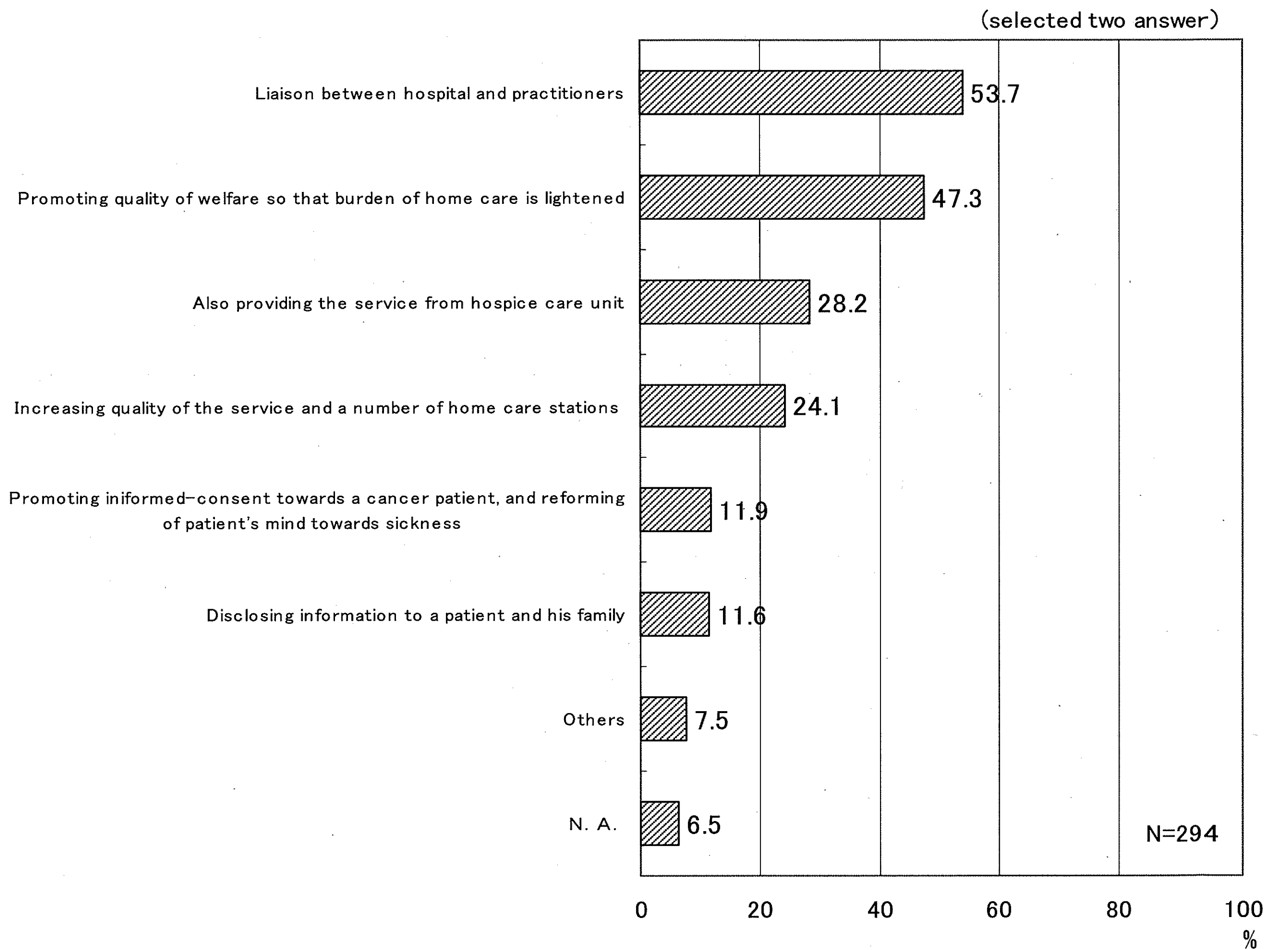

figure12 Necessary condition in carrying out hospice home care

necessary to provide the necessary information for a patient and his family (11.6%) (Figure 12).

Of the 75 doctors who have already provided hospice home care, 48 doctors suggested that social welfare should be improved (64.0%); 31 of them regarded the linkage among hospital, practitioners and local medical association as a very important factor (41.3%); and 18 doctors cited that the number and quality of home care stations have to be increased (24.0%).

There was a significant difference between the opinions of doctors who carry out hospice home care and those of are doctors who do not ($p<0.01$). Other 22 doctors considered that it is necessary to reform medical insurance systems, to improve regulations, and to secure financial resources (7.5%).

6. What should be prioritized when providing hospice home care? (N=294)

Two answers were asked to choose. The majority of the result are as follows; 219 doctors considered it is palliative care to ease a patient's discomfort and severe pain (74.5%), 174 of them believed that it is companionship and support for a terminally ill patient in realizing his own way of death (59.2%) and 133 of them considered that it is to provide a dying patient and his family with the convincing medical therapy and the nursing (45.2%). On the contrary, there are only two doctors who considered it as aggressive therapy and medical treatment (0.7%) and the only one doctor think it is a medical therapy to aim at prolonging life (0.3%) (Figure 13). Other opinions are to respect what a patient and his family's

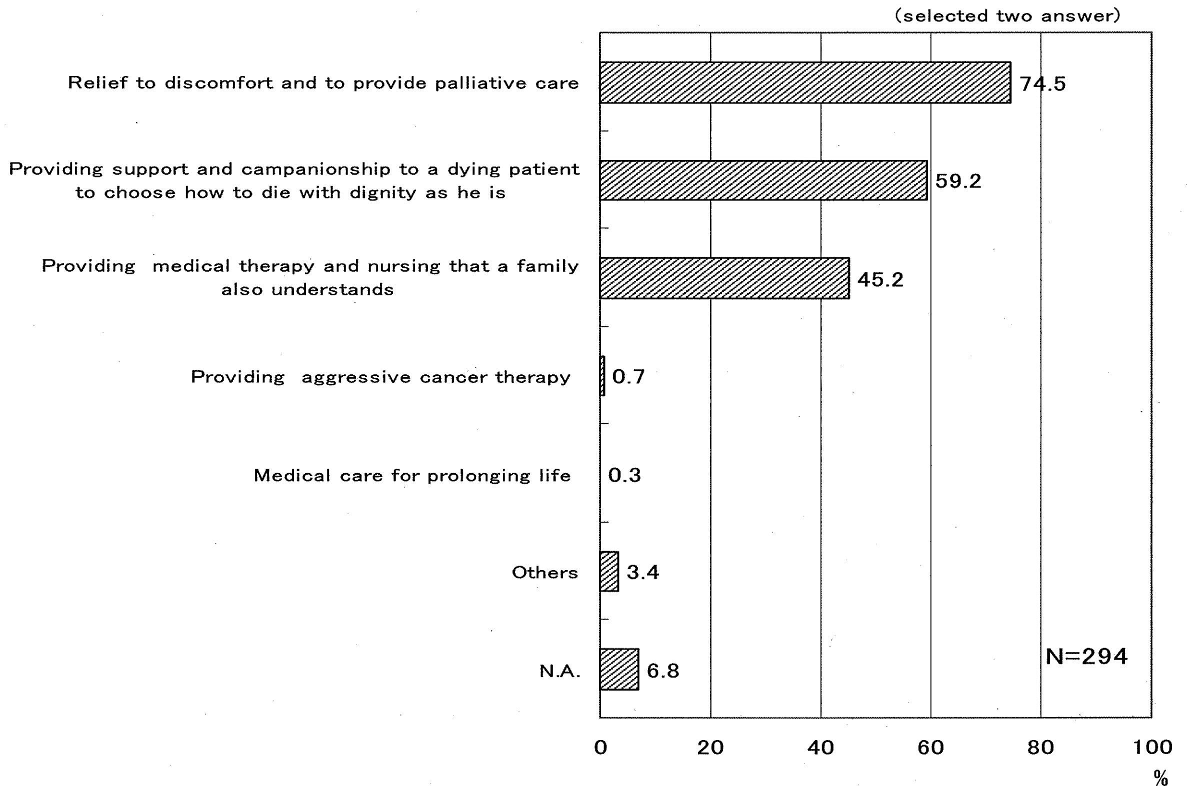

figure13 What should be accounted the most in providing hospice home care?

want and their will.

7. Where the center of hospice home care should be? (N=294)

Of the 294 respondents, 102 doctors consider it would be a hospital, adjoining hospice and palliative care units, and department of home care service within a hospital (34.7%), 69 of them consider that it would be better not to choose where the central organization is (23.5%), 46 of them think it is practitioners (15.6%) , 41 of them think it is a home nursing care station (13.9%), and 28 of them regard a hospital as the center (9.5%) (Figure 14). However, 34.7% of doctors who have already carried out hospice home care; believe that it is better not to decide where the center is, and 30.7% of them think it is a practitioner. Eighty-nine doctors, who do not provide the service, regard a hospital and the adjoining palliative care unit and home care station as

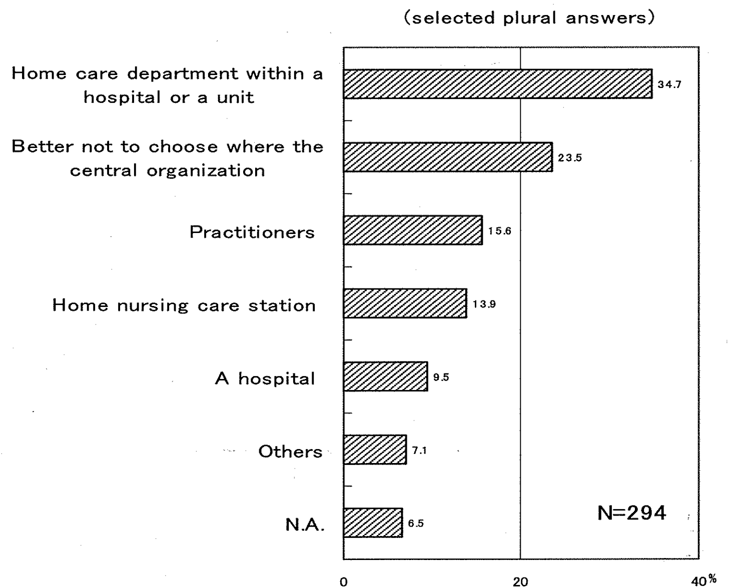

figure14
Where should be the center of providing hospice home care?

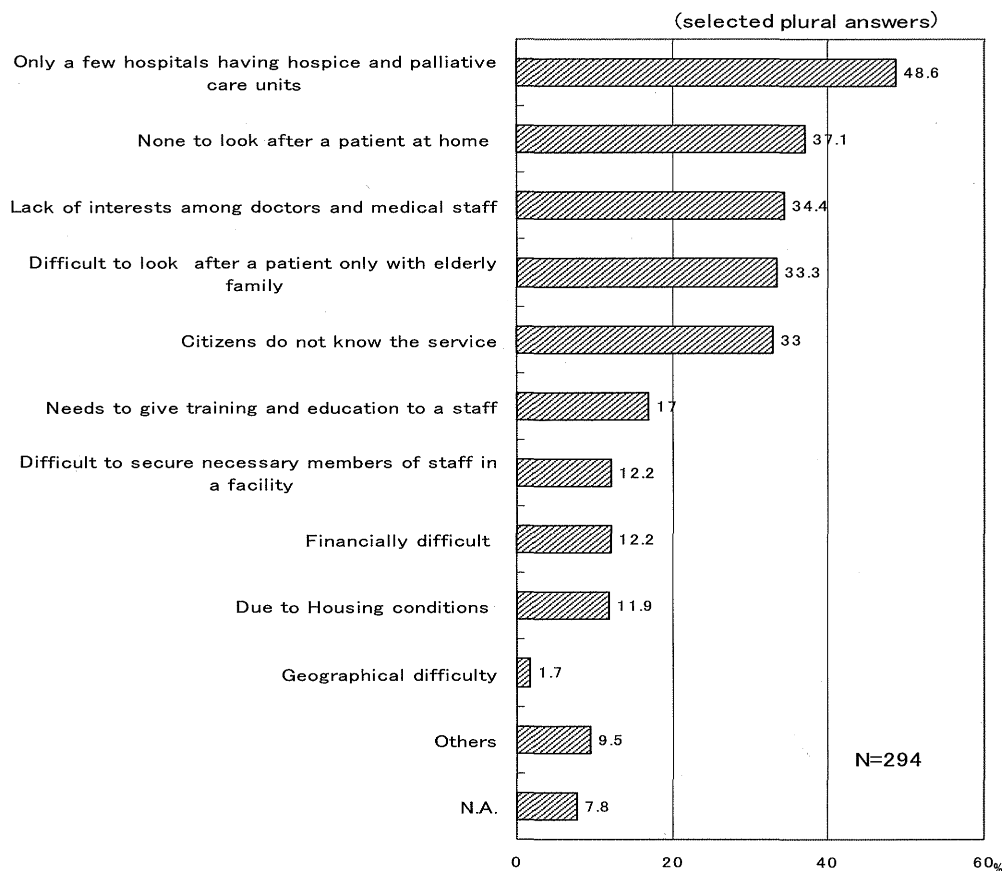

figure15 Difficult reasons in practicing home care in Shiga prefecture

the center(40.6%), 43 of them consider it is better not to determine where the center is (19.6%), 31 of them think it is home care station(14.2%), 23 of them think it is a practitioner (10.5%). There was a significant difference between the two groups ($p<0.01$).

8. Difficulty in providing hospice home care in Shiga Prefecture

The respondents were asked to select all that apply and the results are as follows (Figure 15) : Of all the respondents,

1. 143 answered that there are a few hospitals having hospice and palliative care unit (48.6%).
2. 109 answered that in terms of nursing, a patient does not have a family to look after him all the time (37.1%).
   98 answered that there are many families in Shiga Prefecture whose members are only elderly so that they cannot look after a patient at home (33.3%).
3. 101 answered that many medical specialists are not interested in the service in Shiga (34.4%), but also 97 says that citizens of Shiga do not know what the service is, either (33.0%).
4. 50 indicated that education and training of the medical staff is necessary (17.0%), 36 answered that it is difficult to secure the number of the staff (12.2%).
5. 35 indicated that living condition of the patient makes it difficult (11.9%). 36 pointed out financial difficulty (12.2%), and 5 pointed out geographic difficulty (1.7%).
   Twenty-eight of them wrote down their opinions; including no financial advantages; the needs of expanding a range of work by nurses through relaxing regulations; reduction in the govern - mental budget for medical insurances, medicine and welfare; and lack of knowledge and information about a patient and his family. Some people still

find the service disreputable in the local community.

9. Practitioner's thoughts towards hospice home care.

Of the 294 respondents, 157 (53.4%) found it difficult to provide home hospice care for the following reasons (in the order of numbers of respondent):

1. Physically and emotionally impossible
2. It is necessary for a patient and his family to keep strong will and to understand and corporate each other with the team of medical staff.
3. It is necessary to have a close contact with other medical facilities.
4. It is difficult to deal with a patient well enough.
5. It is necessary to have mutual trust and respect between the team of doctors and a patient and his family.
6. A patient and his family prefer to be in a hospital.
7. Not specialized in hospice and palliative care.
8. Doctor should change and improve their consciousness towards medical therapy.
9. It is impossible under the current medical system.
10. The family has to shoulder a big burden to look after the patient.

Ⅶ Consideration

In Japan, cancer (malignant organism) treatment has been advancing day by day with the invention of new drugs and developments of medical technologies. Because of this progress, the survival rate has been dramatically increased. On the other hand, People have gotten more interested in the idea of hospice care, which evaluates QOL (Quality of Life), rather than aggressive treatment aimed only at prolonging the patient's life.

As a result, 140 hospices and in-patient palliative care units have been established in Japan since April 2005[4], and it is considered that the number will grow steadily.

With the increase of in-patient palliative care units, it is reported that from a terminal cancer patient's point of view, his own home is a more suitable place to live the rest of their life than spending time in a hospital unit[5) 6)]. In fact, for the surveys asking where they would prefer to stay and die, a lot of answers are something like "would like to spend the rest of my life at home," or "would like to die at home"[7)~14)]. Nevertheless, despite the increasing number of hospice home care reports, the reality is that large number of terminal cancer patients still die in the institution — mainly in a hospital[15]. The patients who were able to die at a hospice/palliative care units amounted to only 4% of the total death rate[16], and the number of those who can die at home is still minimal. There are cases where a patient and the family wished to be cared for at home but ended up dying in an institution because of the missed chance.

This survey result indicates that obstacles in carrying out hospice home care within Shiga Prefecture are as follows:

In the region the number of hospitals that have adjoining in-patient hospice and palliative care units is limited. There are only a few mainstay hospitals which can accept patients immediately for the case of emergency and for the treatment that suits the disease advancement. It is also necessary to set up an educational organization that can teach and train medical workers to implement hospice home care and an organization that can play a central role in providing the service for those who need it.

To conduct hospice home care service, the following three absolute conditions will be required of a patient and his family[17]:

1. A terminally ill patient's strong will (to stay and die at home).
2. Their family's strong will.
3. Their family's capability to take care of the patient consistently until the end.

The results of this survey also indicates that the above three conditions are considered necessary for the doctors to carry out the service since 82.7% of the respondents believe that a terminally ill patient and their family have to have a very strong will, 41.3% of general practitioners point out that someone must be at home to nurse a patient all the time, and 32.0% of them regard palliative control at home as an essential factor to conduct hospice home care service. Other opinions are that all medical staff who provide hospice home care must have the energy and passion necessary to provide a dying patient with emotional support and consideration as well as make an effort to meet the patients' requests and needs. Or the staff has to make a dying patient and his family understand well about the fact that there is a limit of what hospice home care can do. A patient's home has to be

fully equipped in such a manner that he is able to receive intervenes transfusions of home intravenous hyperalimentation (IVH) and continuous morphine injections. Therefore, as pointed out as above, to carry out hospice home care service, it is required to meet various conditions as well as to have a much higher level of medical treatment.

On the other hand, concrete medical acts performed in hospice home care are intravenous transfusion, pain control and the treatment in case of emergency situation, in addition to a regular house call. Especially, regarding to the intervenes transfusion, a medical staff dedicated to the service is under great pressure. They are kept long hours at the patient's home, coordination and scheduling with visiting nurses, physical distance (7km is too far) to get to a patient's home, and technical anxiety of providing IVH.

Japanese medical laws regulate who can medical treatments such as injections, and manage and prescribe pain control agents, including narcoctics. At present, a nurse is allowed to give a patient injection or intervenes transfusion only with medical doctor's direction. However it is prohibited for a nurse to conduct them by her own judgment depending on a patient's condition. In Europe and the U.S., the role of the nurse (who has a Master's Degree), who provides hospice care has been expanded in the regulation so that she is able to provide a patient medical treatment without having a medical doctors' direction[18]. I believe that it is time for Japan to discuss providing nurses with special training and education to bring them up to be experts and legally expanding hospice home care.

The result of this survey also indicates that private practitioners started hospice home care service, as a family of a dying patient prefers the service more than the patient himself, and it shows that the issue is linked with the issue of whom to be notified of the name of the illness. On one hand, a terminally ill patient is able to live life fully when he has hospice home care, it also requires the independence on the part of the patient and his family. Therefore, prior to the survey, it was assumed that it would be essential for a doctor to inform a patient of the name of the illness; namely, cancer and the condition. However, looking at the result, only 13.3% of doctors answered that informed consent is essential to provide hospice home care. Many doctors consider it is possible for them to provide hospice home care service for a dying patient and his family when he is elderly. Yet, a reform of the nation's medical measurements is another factor that hospice home care has been started, as local hospitals and home doctors become connected with each other much closer, and a patient stays less at a hospital than before for the sake of reform.

219 doctors (74.5%), who have not provided hospice home care,
cited the reasons as follows: No request from a patient, their family and a local hospital yet. Shortage of medical staff, and financial burden; no experience with the service; the medical department they specify is different; the doctor is too old. Without knowing the concept of the service, the practitioner has already taken it for granted to provide patients with the service. It has not been long enough since a doctor started his practice so that the system has not been ready to cope with hospice home care. He has never heard of the service. It is impossible to cope with it under the current system. The service should be provided with special institutions/facilities. On the other hand, 116 doctors (53.0%) consider it necessary to carry out hospice home care. There are 27 doctors (12.3%), who do not consider it necessary to provide hospice home care, but the reason they are not keen on the service is that they are not an expert on hospice care. They do not have a patient who hopes to receive the service. It only depends on strong will and understanding of a patient and their family, The doctors themselves are so old that they are not able to provide the service. From the answers, it is assumed that practitioners generally hope to provide hospice home care service if both terminally patients and his family are keen.

The survey result also revealed that there are many problems and obstacles for a single practitioner or facility to carry out hospice home service independently. It is thought that hospice home care service should be carried out with the further promotion of linking among doctors working at hospitals, private practitioners, and local medical associations. For example the introduction so-called Open System with the increase of beds at in-patient hospice/palliative care units and house calls of medical workers including nurse from the station which is based at

those facilities to provide medical care for patients staying at home could lead to a smooth transfer to hospice home care. It is also important to inspire local people and to secure the number of experts through specialist education and training.

I have done another survey towards practitioner and home-visiting nurses in Wakayama Prefecture in 2000[19)20)21)]. The background of the prefecture is similar with Shiga Prefecture. In Wakayama, the rate of aging population in the area was 20.0% at that time. The main industry of the local area was agriculture (orchards), fishery, forestry, and there are some depopulated towns and villages.

From the result of the survey answered by 238 practitioners in Wakayama (53.0% answered), 97 practitioners (41.0%) provided hospice home care, and 141 practitioners (56.0%) did not provide the service. Although the result is similar to that of Shiga as a whole, the number of practitioners who provide hospice home care was 1.6 times more than that of Shiga Prefecture.

The problems that Wakayama Prefecture had were as follows:

1. Lack of knowledge towards the service among patients, their family and medical staff.
2. Weak links among local residents, local areas, and medical staff.
3. There is no core institution for the service (in 2001, a palliative care unit was established in Wakayama Prefecture Hospital).
4. There is no member of the family to nurse the patient at home.
5. Lack of training and study programs for the service.

I have considered that I will not be able to get a definite answer until I get a result of a survey in an urban area. However, it is true that the two prefectures face similar problems. Those problems are still left unsolved. So I believe that unless the core problems are not solved, the practice of hospice home care service will be in a difficult situation. At a present, there are the only three hospitals that have a palliative care unit: Shiga Medical Center for Adults, Hikone Municipal Hospital, and Otsu Municipal Hospital. I believe that if at least one palliative care unit exits in each medical territory in the prefecture, the system employed by Otsu City[22)] which enables the linking of a hospital and a practice can be set up in other areas, and into its framework institutions and organizations related to home hospice care can be integrated.

In Shiga Prefecture, 30.5% of people die of cancer and it is ranked the first as the cause of death. Yet there are 30 towns and villages where the rate of the aging population is higher than 20%[2)]. Therefore, it is predicted that the region has a basis of increase in the number of people who would need hospice home care service, and I hope that the local government as a whole will engage in establishing hospice home care service soon.

Ⅷ Conclusion

A condition to carry out hospice home care is as follows:

1. To set up a hospital providing emergency service and according linking between a practitioner and hospital.
2. To increase the number of hospice and palliative care units and hospitals in the prefecture.
3. To provide a special training and education of hospice home care for medical staff.
4. To facilitate a mutual understanding among medical staff and a patient and his family.
5. To inspire local people about hospice and palliative care, and to disclose and provide information about the service.

To practice hospice home care, it is necessary to discuss how main hospitals in the working areas or the prefecture and the local governments get involved in the program, and how concrete each medical organization can link up with each other since there is a limit for one practitioner to provide hospice home care service. On the other hand, it should be discussed whether or not a patient and their family really need hospice home care in consideration of the issues related to a preference on the part of a patient and his family towards a in-hospital treatment, nursing care caused by aging, and the psychological and educational status of patients and the family toward hospice home care.

Acknowledgment

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(Summary)

The Research on the Condition of Home Hospice Care in Shiga Prefecture - From a questionnaire to general practitioners -

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Background The majority of terminal cancer patients still die in general wards of hospitals; those who die in hospices and palliative care wards account for only some four percent of the total. It is considered the most appropriate for terminal cancer patients to receive care at home, enabling them to live out their remaining days in a meaningful way. In order to fulfill such patients' wish to die at home and their families' wish to care for them at home, a home hospice care system must be established that encompasses pain management and sufficient personal care for the patients, as well as support for their families, who are present at the death. The establishment of such a system requires understanding of physicians' views on this issue, identifying problems regarding physicians' cooperation with hospitals, and shedding light on other issues that should be addressed.

bjectives To clarify the current situation of home hospice care in Shiga Prefecture, where the aging rate is 17.3%, as well as to review issues and problems to be addressed in establishing a home hospice care system in local communities, by analyzing the results of a questionnaire survey of general practitioners, who should play a leading role in supporting home care.

Method A questionnaire survey on home hospice care was conducted of 772 general practitioners in Shiga Prefecture by postal delivery and collection.

Results Of the 294 respondents, only 75 (25.5%) actually provided home hospice care services. Of the remaining 219, however, 116 (53.0%) admitted the need for such services. The 75 practitioners see 1.9 patients each on average, mostly in response to requests from patients' families and hospitals. They generally visit the patient's home to administer fluid replacement, provide pain management and respond to emergencies. Although they have their own contact systems for emergencies, some replied that it is impossible to prepare for response to their patients' needs around the clock, and that even if they could, it would be too much of a burden, both physically and mentally.

The respondents feel that further promotion of home hospice care services requires, in addition to phy sicians' capability, strong demand from patients and their families, and sufficient numbers of caregivers, as well as close linkage among practiti oners, hospitals and local medical associations.

Some hoped that palliative care wards and visiting nurse departments of hospitals could play a leading role. These respondents felt that the current shortage of hospices and palliative care wards in local hospitals contributes partly to the difficulty in promoting home hospice care.

Conclusion The survey revealed that the following factors are essential in establishing a home hospice care system: core hospitals that are always ready to accept patients showing sudden change in condition; education and training facilities for medical professionals; facilities that provide integrated services for home hospice care; and palliative care wards and hospices that cooperate with general practitioners.

Key Words Home hospice care, general practitioners, terminal cancer patients