

## ORIGINAL RESEARCH

# Inhibitory factors and problems associated with uniform access to cancer care: Perceptions of certified nurse specialists in cancer nursing

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## ABSTRACT

To elucidate the factors that obstruct uniform accessibility to care when oncology clinical nurse specialists (OCNSs) engage in medical care and to devise solutions for these obstructions. OCNSs enhance the quality of medical care, conduct activities as multidisciplinary coordinators, and provide public policy-related advice to maintain and improve the general population's health. Therefore, OCNSs' opinion is highly regarded, particularly in clinical setting. This study extracted and investigated the perceptions of OCNSs regarding factors inhibiting uniform access to care on the basis of a questionnaire with open-ended questions. Upon receiving the institutional review board's approval, a questionnaire was distributed among 483 participants. Of these, 211 OCNSs affiliated with Core Oncology Centers who returned the filled questionnaire forms were enrolled. The recovery and effective response rates were 43.7% and 63.5%, respectively. Data were collected from the survey forms and subjected to qualitative and descriptive analyses. Inhibitory factors were categorized into the following five categories: (1) education and training systems; (2) medical specialties and workforce; (3) standard of medical care; (4) insufficient understanding on the part of administrators and the organization; and (5) policy. Each factor was further categorized into subcategories to elucidate the factors inhibiting universal access to care. Factors related to education and training systems affect factors related to medical specialties and manpower, leading to an imbalanced distribution of personnel between regions and facilities.

**Key Words:** Oncology clinical nurse specialists, Cancer care, Uniform access, Public policy, Core oncology centers

## 1. INTRODUCTION

With the aging population, the number of patients with cancer and related mortality is expected to increase in Japan. Disparities in cancer care and support are seen at the regional level and among medical facilities across the country, and many patients are consequently unable to receive the care and support that their circumstances demand.<sup>[1]</sup> Therefore, to provide high-quality cancer care throughout the country,

Prefectural Core Oncology Centers and Regional Core Oncology Centers (hereafter, Core Oncology Centers) were established according to the Basic Plan to Promote Cancer Control Programs, which has the strategic goal of ensuring uniform access to cancer care. To further promote uniform access, Core Oncology Centers independently accredited by individual prefectures also began to be developed.

The Basic Plan to Promote Cancer Control Programs intends

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to improve uniform access and cancer care by recruiting experienced personnel in medical facilities, particularly nurses who are certified nurse specialists in cancer nursing (oncology clinical nurse specialists, OCNS).<sup>[1]</sup> However, per the Investigative Committee on the promotion of cancer care accessibility,<sup>[2]</sup> training of additional personnel to overcome the shortage of oncology specialists and other co-medical staff, primary cause of regional disparities in cancer care is a pressing issue. One of the co-medical staff members included in this assessment are OCNSs. Currently, there are no OCNSs in the three prefectures of Aomori, Kagoshima, and Fukui, and their overall geographic distribution is unbalanced throughout Japan.

Owing to their pivotal position between multiple specialists and the cancer care team, OCNSs play a multidisciplinary role of leadership and coordination. Furthermore, the objective of their activities is to improve the quality of medical care, to recommend policies to maintain and improve the health of the general population, and to work toward practice.<sup>[3]</sup> Therefore, OCNSs are believed to have an understanding of multidisciplinary activities and teams or of the overall facilities and are expected to have a broad understanding of the present state of cancer care. Hence, they can provide useful knowledge when examining issues related to

uniform access. Despite several state-funded surveys and studies conducted earlier,<sup>[4-9]</sup> surveys on cancer nursing issues have been limited to outpatient departments of Core Oncology Centers.<sup>[10]</sup> Consequently, no study has been conducted on cancer care accessibility from the viewpoint of OCNSs. Therefore, through a qualitative and descriptive analysis, this study aims to investigate the inhibitory factors of uniform access according to the detailed responses of OCNSs.

## 2. METHODS

### 2.1 Data collection

OCNSs affiliated with Core Oncology Centers were provided a questionnaire (see Table 1), written description of the study, and stamped self-addressed envelopes. They were requested to return their completed questionnaire via mail within 2 months of distribution from May 2014 to July 2014. Additionally, participants were sent a letter of request explaining that they were free to choose whether to respond or not and that their decisions would be respected. Additionally, we performed examinations regarding the present conditions of the country. This was done after the questionnaire, because a revision about “the Basic Plan to Promote Cancer Control Programs” was not conducted until March 2018.

**Table 1.** Demographic characteristics (n = 134)

Items	n	%	
Clinical experience as nurse (years)	5-9	7	5.2
	10-14	36	26.9
	15-19	35	26.1
	20-24	34	25.4
	25-29	18	13.4
	30-34	3	2.2
	35-40	1	0.7
Clinical experience as a CNS (years)	0-4	110	82.1
	5-9	21	15.7
	10-14	3	2.2
Position	Manager	44	32.8
	Staff	90	67.2
Total number of CNSs in each affiliation	Palliative care team	54	
	Cancer consultation and support center	40	
	Chemotherapy room	18	
	Radiotherapy room	4	
	Outpatient department	20	
	Ward department	43	
Workplace	Cancer centers	120	89.6
	Other hospitals	14	10.4

### 2.2 Participants

We identified 483 nurses listed in the OCNS registry on the homepage of the Japanese Nursing Association as of Febru-

ary 2014 and whose contact information could be confirmed. Of these, 211 (43.7%) OCNSs returned the questionnaire and were enrolled. The effective response rate of the meaning

the answered in all items was 63.5% (134 individuals).

Table 1 presents the background characteristics of enrolled OCNSs. Mean ± SD years of experience before and experience after becoming a certified OCNS were 18.15 ± 6.15 and 3.22 ± 2.97 years, respectively (excluding those who did not respond in all cases). Distribution by the number of years of experience was 110 nurses (82.1%) at < 5 years and 24 nurses (17.9%) at ≥ 5 years. Position distribution was as follows: 53 nurses (39.6%) worked in administrative positions and 81 (60.4%) in staff positions. The assigned divisions were as follows: 54 were assigned to palliative care teams, 40 to consultation and support centers, 18 to outpatient chemotherapy units, 4 to radiotherapy units, 20 to outpatient divisions, and 43 to hospital wards. Further, their position includes an additional post.

The investigated items have been presented in Table 2.

**Table 2.** The contents of the question

①	Years of experience after acquisition of nursing license
②	Years of experience after acquisition of CNS qualifications
③	Position
④	Working system (multiple answers) Note 1 (palliative care team, cancer consultation and support center, outpatient chemotherapy room, radiotherapy room, outpatient department, ward department)
⑤	Workplace
⑥	Open-ended question on the availability of cancer treatment

**2.3 Analytical methods**

Descriptive statistics were used for the number of years of nursing experience, years since receiving a certification as an OCNS, position, and assigned division. Similarities and differences were identified in the statements related to uni-

form access in the nurses’ descriptive responses. These were assigned codes and organized into subcategories, from which categories were extrapolated. Although the factors were classified according to the categories, this entire process was continually supervised by a researcher experienced in conducting qualitative research. Moreover, every effort was made to ensure the validity of this process.

**2.4 Ethical considerations**

Potential participants were provided with an explanation of this study according to the study plan approved by the medical institutional review boards of the Graduate School of Medicine & Faculty of Medicine, Kyoto University and Kyoto University Hospital. The research purpose and participant benefits were stated in writing, and they were also explained that participation in the research is voluntary and the content of the date is not used for purposes other than for this research. With the return of the questionnaire, it was assumed that the consent of the research participation was obtained.

**3. RESULTS**

**3.1 Factors that inhibit uniform access to cancer care**

Analysis of the descriptive contents resulted in 116 codes, which in turn led to the extrapolation of 15 subcategories. The following five categories were extrapolated: “factors related to the education and training systems” (see Table 3), “factors related to medical specialties and manpower” (see Table 4), “factors related to the standard of medical care” (see Table 5), “factors related to an insufficient understanding on the part of administrators and the organization” (see Table 6), and “factors related to public policy” (see Table 7). Figure 1 shows a diagram of all the factors.

**Table 3.** Factors related to education and training systems

Category	Subcategory (2)	Code (6)	Descriptive contents (6)
Factors related to the education and training systems	Insufficient educational facilities	Differences in the numbers of educational facilities in urban and outlying areas	Causes regional differences in the number of educational facilities for physicians
		Insufficient educational facilities	Insufficient educational facilities
		Shortage of specialized co-medical training organizations	Specialized co-medical educational organizations are not sufficient
	Insufficient educational and training systems	No standards or programs for all types of medical jobs	I think it would be appropriate if there were systematic rules and programs for all medical specialties such as those provided by the OPTIM Project
		The training system for medical practitioners is insufficient	Physician and pharmacist training facilities are insufficient
		There is no comprehensive training for all medical practitioners	I would like the national government to conduct training of medical practitioners separately by field of medicine

**Table 4.** Factors related to medical specialties and workforce

Category	Subcategory (2)	Code (23)	Descriptive contents (30)	
Factors related to medical specialties and workforce	Personnel disparities by region	Difficulties in finding personnel in some regions	Personnel shortages; people avoid outlying areas Difficult to hire personnel	
		Insufficient incentive to hire personnel in the outlying areas	I hope that more is done to promote hiring personnel in remote areas	
		Shortage of workforce in outlying areas	There is a shortage of workforce in outlying areas	
		There is no budget for increasing workforce in outlying areas	Outlying areas are suffering because there is no budget for increasing workforce	
		There is a shortage of people in outlying areas who are appropriate for the jobs required	There is a shortage in outlying areas of personnel who are appropriate for the jobs required	Because there are no people in outlying areas, no additional payment is available, and so the loneliness continues to get worse
			Shortage of physicians in outlying areas	Physician shortage Physician shortage in outlying areas
		Shortage of nurses in outlying areas	Shortage of nurses in outlying areas	
		Medical practitioners concentrate in urban areas	Medical practitioners concentrate in urban areas	Medical practitioners concentrate in urban areas Medical practitioners are concentrated in the Kanto region, which means that people concentrate there even more
			Shortage of comprehensive cancer specialists in outlying areas	Shortage of medical specialists in outlying areas
		Shortage of oncologists in outlying areas	Shortage of oncologists in outlying areas	
		Shortage of palliative care specialists in outlying areas	Not enough palliative care physicians in outlying areas	
		Shortage of psychiatrists in outlying areas	Not enough psychiatry specialists in outlying regions	
		Shortage of OCNSs in outlying areas	Shortage of specialists in cancer nursing in outlying areas	
		Shortage of cancer specialists in outlying areas	Few specialists, such as palliative care physicians, psycho-oncologists, psychologists, and OCNSs, are present in outlying areas	
		Difficult to distribute medical specialists throughout the country because of a disproportionate number of specialists in certain regions	It is impossible to make all regions of the country the same because there are regional characteristics such as differences in the numbers of medical specialists	
		There are more medical specialists in urban areas than in outlying areas	There are large differences in the numbers of medical specialists in urban areas and in outlying areas, which means that uniform access is a long way off	
		In some regions, there is an extremely small number of OCNSs	There is an extremely small number of OCNSs in some regions	
	OCNSs are concentrated in urban areas	OCNSs are concentrated, so there are few in outlying areas		
	Some Core Oncology Centers have no OCNS	OCNSs are concentrated in urban areas so there are some hospitals in outlying areas with no OCNS		
	There are many OCNSs in the Kanto Region, so they are not uniformly distributed throughout the country	Many OCNSs are in the Kanto Region, so there is the need for uniform access throughout the country		
	There are major differences in the number of OCNSs by region	There are major differences in the numbers of OCNSs by region		
	Disproportionate numbers of personnel in facilities	The number of personnel in facilities is disproportionate	The number of personnel in different hospitals is disproportionate even in the same region There are workforce differences between facilities	
		There are differences in the numbers of OCNSs in different facilities	There is a strong impression that Core Centers provide advanced treatment, but there are differences between the Centers in terms of cancer treatment, particularly OCNS, care	
There are more OCNSs in urban areas than in outlying areas		OCNSs are concentrated in centralized hospitals and there are none in hospitals in outlying areas, so it would be difficult to ensure uniform quality of care		

**Table 5.** Factors related to the standard of medical care

Category	Subcategory (7)	Code (21)	Descriptive contents (28)	
Factors related to the standard of medical care	The level of medical care in different regions is not the same	There are differences in the standard of medical care by region	The issue of regional differences must be considered There are differences in the level of medical care by region	
		The actual level and required level of medical care do not match in some regions	There are regional differences because the designated requirements and the actual conditions do not match There are many difficulties related to the medical care available in some regions due to regional conditions	
		There are differences between the standard of medical care in urban and outlying areas	I wish that the systems could be adjusted on the basis of an understanding of the actual conditions in urban areas and outlying areas There are major differences in the medical care available in urban areas and outlying areas	
		Differences in the standards of medical care at different facilities	There is a tendency for patients to concentrate on Cancer Centers	There is a tendency for patients to concentrate on hospitals specializing in oncology
	Patients are concentrated in Core Oncology Centers		Patients are concentrated in large hospitals	
	There are differences in the level of medical knowledge and skill in different facilities		It is difficult to ensure uniform levels of knowledge and skills in different facilities	
	There are major differences in the standard of medical care provided at different facilities		There are major differences in the standard of medical care provided at different facilities	
	There are differences in the human factors and equipment available at different facilities		There are differences in the maintenance systems for the equipment at different facilities	
	There are different standards of medical care at different facilities in the same region		There are differences in the people and equipment available in the same region	
	The links between Core Centers and general hospitals are unclear and there are differences in the standard of medical care		The links between Core Centers and mid-sized hospitals are unclear and there are differences in the standard of medical care There are differences between general hospitals and Core Centers	
	Hospitals in mountainous areas cannot provide the same standard of medical care as hospitals in urban areas		There are medical problems in facilities located in mountainous areas and patients do not get the benefits of uniform access	
	Disproportionate quality of medical care and difficulties in maintaining and improving that quality		Further efforts to improve the quality of medical care are required	Further efforts to improve the quality of medical care are required
			I am not confident that the quality of medical care can be maintained in the future	It will be impossible to maintain the quality of medical care in the future
		Since improving the quality of medical care will be important in the future, it is necessary to improve education and other systems	Since I think quality is the key in the future, improvement is needed, including education	
		The quality of medical care is not being maintained even though policies and requirements are being updated	Quality is not being maintained in accordance with the requirements	
		Although national policies are applied to hospitals, the quality of medical care is not being maintained	The national government makes policies and hospitals, prefectures, and local municipalities execute the policies, but quality is not being maintained	
		Hospitals are making superficial changes but the quality is not improving	Hospitals are making superficial changes by quality is not improving at all	
		When Core Centers cannot satisfy the requirements, it is difficult for them to guarantee the subsidies and personnel required to maintain the quality of medical care, as a result, the quality does not improve	Since Core Centers cannot obtain the things (money, people, etc.), they need to maintain the quality in cases in which they do not follow directions (even if they meet requirements); it is impossible for them to improve quality	
		Insufficient palliative care wards and regional cooperation	Delays in at-home care	Since care has been provided mainly in hospitals, at-home care system is lagging
	Since care has been provided mainly in hospitals, at-home care is lagging			
	Insufficient and delayed regional cooperation systems		Team medical care cooperation throughout some regions is impossible	
			Although it is necessary to ensure that patients can live in outlying areas in the same way they would live in hospitals, there are no such systems for this	
	Shortages and disproportionate distribution of palliative care wards	The overall number of palliative care wards is low		
		There are regional differences in the establishment of palliative care wards		

**Table 6.** Factors related to an insufficient understanding on the part of administrators and organizations

Category	Subcategory (3)	Code (9)	Descriptive contents (13)
Insufficient understanding on the part of administrators and organizations	Insufficient understanding on the part of administrators	Administrators lack skill in assigning personnel	Administrators at Core Centers put their efforts in areas other than cancer
			Administrators need to think about assigning personnel to appropriate positions
			There are no administrators who think personnel training and management are important and can do both
	Insufficient understanding on the part of organizations	Administrators have an insufficient understanding of national policies	National policies and the perceptions of hospital directors do not match
			I wish there were efforts being made to educate administrators to promote improvement
			Hospital administrators have little knowledge and so do not make improvements
	Insufficient understanding on the part of organizations	Differences in administrators' ideas in different facilities	Major differences occur due to the way of thinking by hospital decision-makers
			There is a lack of consistency in organizations' perceptions of cancer care
			Hospitals in outlying areas need a system of education that creates an understanding of their role in supporting cancer patients' lives
	Insufficient guarantee of the status of and insufficient utilization of human resources	Insufficient understanding on the part of organizations of the palliative care team and consultation division	The organizations do not believe that palliative care teams and consultation divisions are necessary
			Facilities are insufficient because of lacking understanding on the part of organizations
			Systems are not improved because organizations do not understand [the need for improvement]
	Insufficient guarantee of the status of and insufficient utilization of human resources	The system to ensure resources is insufficient	If the national government can ensure the uniformity of quality, then I would like them to ensure resources as well
Resources do not contribute to the local community			
Although OCNSs are hospital resources, they do not function as resources for the community			
Insufficient guarantee of the status of and insufficient utilization of human resources	OCNSs are treated poorly	OCNSs are treated poorly. Since I cannot recommend young people to become certified as OCNSs, shortages will occur in the future	

**3.2 Contents of the categories**

The contents of the categories are as follows:

- (1) "Factors related to education and training systems" comprises two subcategories: "shortage of educational facilities" and "insufficient training". These include "Causes regional differences in the number of educational facilities for physicians" or "I think it would be appropriate if there were systematic rules and programs for all medical specialties", such as those provided by the OPTIM Project.
- (2) "Factors related to medical specialties and workforce" comprises two subcategories: "disproportionate geographic distribution of personnel" and "disproportionate distribution of personnel in facilities". These include "Personnel

shortages", such as "people avoiding outlying areas" or "the number of personnel in different hospitals".

- (3) "Factors related to the standard of medical care" comprises four subcategories: "disparities in the standard of medical care by region", "disparities in the standard of medical care by facility", "disparities in the quality of medical care standards and difficulties in maintaining and improving quality", and "disproportionate distribution of palliative care wards and insufficient regional cooperation". These include "The issue of regional differences", "There is a tendency for patients to concentrate on hospitals specializing in oncology", and "Further efforts to improve the quality of medical care are required".

**Table 7.** Factors related to public policy

Category	Subcategory (4)	Code (24)	Descriptive contents (42)	
Factors related to public policy	Insufficient quality assessment criteria for ensuring uniform access	There is no assessment of the certification standards for Core Centers	I wish the national government would carry out qualitative assessments of the certification standards for Core Centers	
		No qualitative assessments of medical care are done	I wish assessments were made of the quality itself	
		There are deficiencies in education related to insufficient assessment of nursing activities	I wish there were more venues where nurses could utilize their unique functions. I would like nursing education to include this	
		It is difficult for nurses to develop because their remuneration does not reflect the actual work they do	Nurses will not grow if their remuneration does not consider the quality of their unique work	
		There are no qualitative assessment criteria	I would like the number of researchers working on nursing development to increase and for them to develop a quality assessment	
		Good treatment at Core Centers	Regional Core Centers receive more subsidies than general hospitals	
		Insufficient subsidies	Since there is not enough subsidy, consultation and support centers cannot fulfill their duties	
			The way budget money is distributed is not clear-cut	
		It is difficult to carry out activities due to the lack of subsidies	Medical facilities are suffering because of the lack of budget allotments, which interferes with their activities	
		It is difficult for small- and mid-sized hospitals to receive additional remuneration	Because large hospitals have many departments and types of jobs, it is easy for them to receive remuneration funds, but small- and mid-sized hospitals find it difficult to receive remuneration funds	
		There is little awareness of requirements	There is little awareness in hospitals of cancer patient counseling fees and lymphedema guidance fees	
		It is difficult to create systems for requirements	It is difficult to create operating systems to carry out the designated requirements	
	Negative image of designated requirements and the remuneration system at medical venues	Getting a strong impression that superficial efforts are made to satisfy requirements, but they are without sufficient content		
		Designated requirements are gradually becoming stricter. If they continue this way, it will become impossible to satisfy them		
		New requirements are too stringent		
		The designated requirements are becoming increasingly strict, and so satisfying the requirements controls everything some people in the hospital do		
		The medical remuneration calculation methods are too strict		
		It is difficult for acute care hospitals to satisfy the requirements		
	Insufficient development of public policies and implementation difficulties	Cancer treatment is limited by what is covered by the medical insurance system	There are limits to what can be done by performing tasks approved by the medical insurance system	
		Differences in the facilities and equipment available at Core Centers and other facilities caused by policy	Since Prefectural Core Centers are not strictly supervised, the burden borne by regional Core Centers remains high	
			Although palliative care centers are required in Core Centers, there are increasing differences between facilities and so general hospitals do not have sufficient equipment available	
		No opportunities to feel that public policy is working for people	There is no sense at medical facilities that efforts toward ensuring uniform access are being carried out	
			There are almost no opportunities to get a sense that policies are working	
		Public policies are not in line with clinical settings	Public policies do not cover all they should	
I would like those who make policies to view issues from the perspective of medical facilities				
Since cancer care measures are not in line with actual conditions and are difficult to carry out, I wish someone would observe medical facilities				
I think it is important for local municipalities to have their own unique policies and assessments, but this creates differences between facilities				
There is a disparity between the standards the national government requires and the systems in place in the organizations that have to carry these out				
Although we are struggling to meet the national government's requirements, we have reached our limit				
It requires time for clinical facilities to carry out policies		It is extremely difficult to match policy with the actual conditions in facilities		
	There are many problems with the system and I have many doubts			
	There are demerits to trying to make progress with policies. It is necessary to adjust methods so that they are appropriate to each facility			
	It requires time for facilities to carry out the measures determined by the national government			
	The designated requirements are too strict and are not in line with actual conditions			
	We are restricted by the requirements, and so I doubt whether those making the requirements know anything about medical facilities			
The designated requirements are too strict and not in line with conditions at clinical settings	While Core Centers may be able to carry them out, every time we get new requirements, the staff becomes exhausted and further disparities between facilities are caused			
	The national government should encourage local municipalities to use palliative care more widely			
Insufficient cooperation between the national/local governments and medical facilities	Insufficient cooperation among the national government, regional/local governments, and facilities in terms of cancer care	The fact that the prefectural government, national government, and hospitals do not cooperate generates problems for cancer care		
	Misunderstandings and lack of information provided to the general public regarding cancer care	Insufficient knowledge of cancer care on the part of the local community	Lack of knowledge on the part of the local community makes it difficult to see the way of thinking regarding matching community Core Centers in urban areas	
Insufficient information about cancer care provided to the local community		The national government does not carry out initiatives designed to increase the understanding of the general public regarding the current state of cancer care		
Misunderstandings of palliative care on the part of local community residents		Patients have insufficient knowledge of palliative care		
Lack of information provided to the local community regarding palliative care		The general public does not understand. The national government needs to do more (people still think that palliative care means care immediately before death)		

(4) “Factors related to an insufficient understanding on the part of administrators and organizations” comprises three subcategories: “insufficient understanding on the part of administrators”, “insufficient understanding on the part of entire organizations” and “insufficient guarantee of the status of and insufficient utilization of human resources”. These include “Administrators at Core Centers that put their efforts in areas other than cancer”, “Hospitals in outlying areas needing a system of education that creates an understanding of their role in supporting cancer patients’ lives” and “If the national government can ensure the uniformity of quality, then I would like them to ensure resources as well”.

(5) “Factors related to public policy” comprises four subcategories: “insufficient qualitative parameters for ensuring

uniform access”, “deficiencies in the public policy development and implementation difficulty”, “insufficient cooperation between national/local governments and medical facilities” and “misunderstanding by the general public of cancer care and insufficient supply of information to the general public”. These include the following: “I wish the national government would carry out qualitative assessments of the certification standards for Core Centers”, “Regional Core Centers receive more subsidies than general hospitals”, “The national government should encourage local municipalities to use palliative care more widely” and “Lack of knowledge on the part of the local community makes it difficult to see the way of thinking regarding matching community Core Centers in urban areas”.

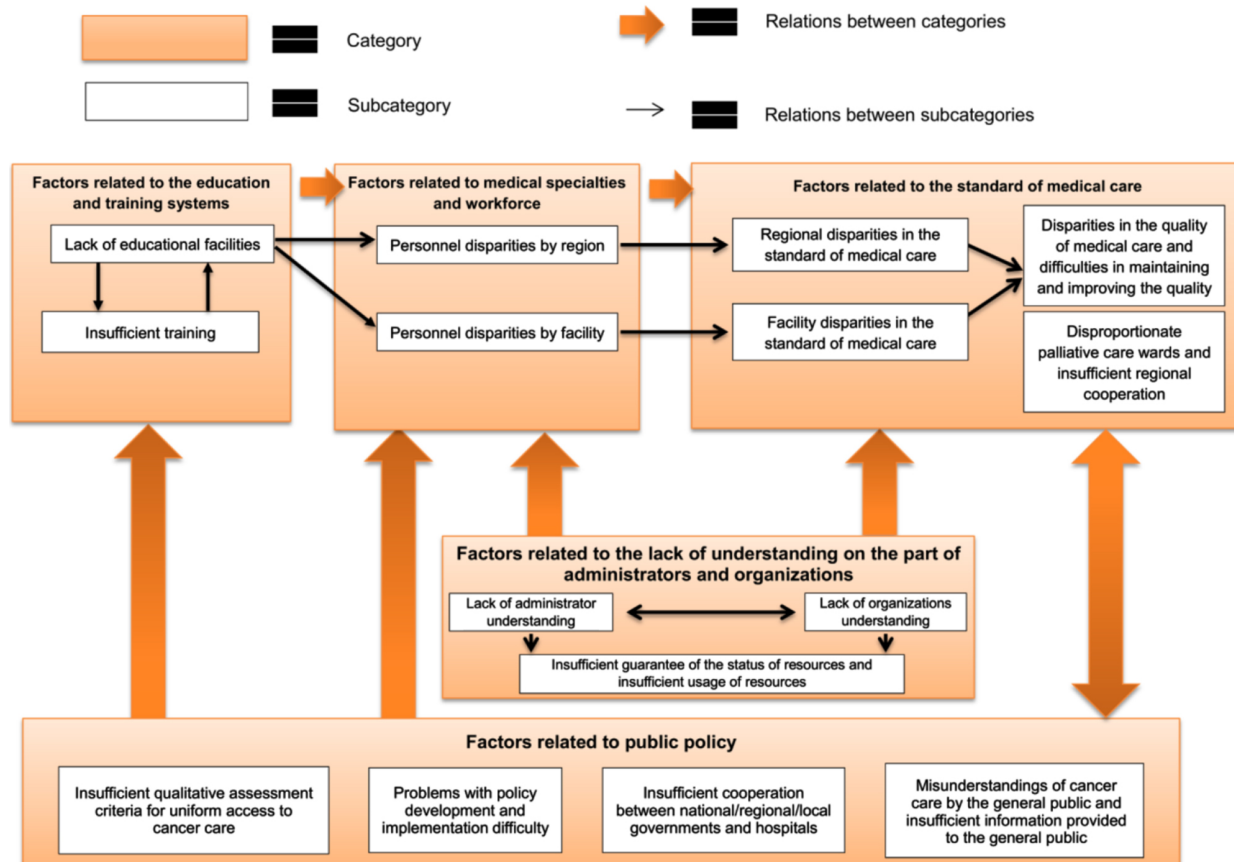


Figure 1. Diagram depicting all the factors considered in this study

## 4. DISCUSSION

### 4.1 Factors related to education and training systems

#### 4.1.1 Shortage of educational facilities

Problem: The Japanese government is promoting the Cancer Professional Promotion Training Plan to achieve uniform access; however, in Hokkaido, the majority of specialists in cancer care are concentrated at flagship hospitals in urban

areas, making it difficult for rural patients with cancer to receive specialized cancer care.<sup>[11]</sup> Measures: Therefore, the Cancer Professional Promotion Training Program needs to train personnel in remote regions. Owing to limited OCNS training facilities in remote areas of Japan, such as Aomori and Fukui Prefectures,<sup>[12,13]</sup> the government needs to increase the number of training facilities in these regions to ensure that cancer care is uniformly accessible.



#### 4.1.2 *Insufficient training system*

**Problem:** Basic Plan to Promote Cancer Control Program aims in “relieving the suffering experienced by all cancer patients and their families and simultaneously maintaining and improving the quality of their lives while under medical care.” To improve palliative care function and consultation and support functions, it is necessary to improve quality of life (QOL). Ensuring uniform access to cancer care also provides physicians with a common foundation in the form of standard operating procedures.<sup>[14]</sup> The Outreach Palliative Care Trial of Integrated Regional Model (OPTIM; a government-provided cancer training program for medical professionals) Project, a qualitative assessment-based national survey, developed a comprehensive regional palliative care program applicable in any region of the country and created a handbook, the OPTIMIZE Strategy, to be used regardless of the local systems in place.<sup>[15]</sup> The importance of equivalent standards was underscored by opinions such as “it would be appropriate to utilize systematic rules and programs such as those provided by OPTIM,” suggesting that such standards lead to high-quality care provided by medical practitioners. Additionally, a qualitative review of the Gold Standard Framework reported that most medical professionals experienced improvement in communication and coordination among medical professionals than in symptom control or direct contact with patients.<sup>[16]</sup> Moreover, regardless of training seminars, such as Palliative care Emphasis program on symptom management and Assessment for Continuous medical Education and Pharmacy Education for Oncology and Palliative care Leading to happy End-of-life, physicians and pharmacists attended felt that “the training seminars for physicians and pharmacists were insufficient.” This was possibly because of the effects of issues such as strict restrictions on the use of money, including the inability to use valuable subsidies to pay for training costs and related travel expenses.<sup>[17]</sup> Measures: Easing restrictions on the use of subsidized funds and thereby creating an environment in which it is easier for medical practitioners to attend training seminars can be expected to improve their knowledge and skills and concurrently lead to smoother communication among them, enhancing the quality of medical care overall. Therefore, further efforts can be made to investigate the use of government subsidies as well as criteria and guidelines, including elements of OPTIM, to ensure uniform access.

### 4.2 *Factors related to medical specialties and workforce*

#### 4.2.1 *Disproportionate geographic distribution of personnel*

**Problem:** Currently, many hospitals are facing scarcity of medical specialists and staff members.<sup>[17]</sup> Meanwhile, OCNSs are disproportionately concentrated in urban areas.<sup>[13]</sup>

No matter how well equipped a hospital is, if it lacks staff, it will not be able to provide appropriate medical care, thereby affecting its quality of service. Despite the scarcity of interns specializing in pharmacotherapy<sup>[14]</sup> and Core Oncology Centers requiring a psychiatrist on their palliative care team, the current scenario makes it impossible in many cases. Consequently, only handful of facilities other than oncology centers and university hospitals have a psychiatrist on their staff or in their palliative care teams.<sup>[18]</sup> Therefore, even if Core Oncology Centers in regional areas have palliative care teams, there are differences in the type of care provided.

The existence of medical care disparities in various regions of Japan,<sup>[19–22]</sup> along with regional differences in fiscal resources and public policy priorities in different prefectures,<sup>[10,17]</sup> has been elucidated in previous studies. Furthermore, there is a disproportionate concentration of medical specialists and specialties in urban areas.<sup>[23–25]</sup> Opinions that there are “shortages of doctors in outlying regions” and that “OCNSs are concentrated in urban hospitals and not present at all in regional hospitals” coincide with reality. Measures: Therefore, it is necessary to solve this problem because it cannot be solved by hospital organizations alone owing to limitations on what they can do from an administrative standpoint.

#### 4.2.2 *Disproportionate distribution of personnel in facilities*

**Problem:** Approximately 42 facilities in Japan employ multiple OCNSs<sup>[8]</sup> who coordinate with each other and cooperate with certified nurses (CNs) for various activities. On the other hand, many facilities do not even have a single clinical nurse specialist (CNS) or CN on staff, indicating a significant problem of disproportionate distribution of personnel in facilities.<sup>[26,27]</sup> Reportedly, only approximately 50% Core Oncology Centers employ OCNSs.<sup>[2]</sup> Owing to their utilization as employees and the employment environment, often many people who complete the CNS education program do not take the certification examination.<sup>[26,28]</sup> Reportedly, 60% nursing administrators responded that they have no plans to hire a CNS,<sup>[28]</sup> and the selection of a workplace where the skills of OCNSs can be utilized is a problem for those who have completed the education program and CNSs. Measures: Apparently, it is important for nursing administrators to have a better understanding of the issue of disproportionate distribution of OCNSs in medical facilities.

**Problem:** To ensure improvement in cancer care, it is essential to increase the awareness and develop the skills of those involved in cancer care.<sup>[17]</sup> However, notably, many medical facilities have insufficient policies to raise the awareness and improve the skills of their staff members involved in cancer

care.<sup>[14]</sup> With opinions such as “getting a strong impression that Core Oncology Centers provide advanced therapy, but in terms of cancer treatment, particularly cancer patient care, there are differences between facilities” and that different clinical settings include various types of facilities and have insufficient policies, it can be inferred that there are some facilities that are unable to improve the quality of cancer care they provide. As of April 2015, Core Oncology Centers have been certified as Regional Cancer Treatment Centers that cooperate with each other to treat patients. However, formulation of some policies is still required for general hospitals, which are excluded from this system. Measures: In the future, it will be necessary for the medical specialties to lead the improvement in the quality of care provided at hospitals. Core Oncology Centers specifically need an environment wherein specialists in all fields can utilize their skills. Meanwhile, there needs to be a “backup system” that will facilitate Core Oncology Centers in providing knowledge and technical expertise to general hospitals. The creation of interrelationships between Core Oncology Centers and public hospitals is an important aspect of ensuring uniform access to cancer care.

### 4.3 Factors related to the standard of medical care

#### 4.3.1 Disparities in the standard of medical care by region

**Problem:** A report, “Investigative Committee Report on the Promotion of Uniform Accessibility to Cancer Care,” compiled by the Ministry of Health, Labour and Welfare (2005)<sup>[2]</sup> suggests that the differences between prefectures are not only, in part, because of background factors, such as the degree of cancer progression, but may also be caused by differences in diagnostic and treatment techniques. Other possible factors leading to regional differences include problems with the training of oncologists and co-medical staff. Therefore, the aforementioned “Shortages in medical specialties and manpower” and “Problems related to OCNSs” may be related to these factors. Furthermore, it is challenging for those involved in medical care to obtain information about the medical care functions of other oncology centers, indicating that there are obstacles in inter-hospital and hospital-clinic cooperation. Because the widespread use of medical care and other types of guidelines is not being promoted,<sup>[2]</sup> the cooperation among medical organizations in different regions, creation of inter-regional networks, and collaboration among medical organizations on a national scale are also related problems. Measures: The cooperation of the hospital of the different composition becomes important with an increase of the staff of the future further employment.

#### 4.3.2 Disparities in the standard of medical care by facility

**Problem:** Apparent differences in the medical care provided at different facilities have been elucidated in previous studies.<sup>[19–22]</sup> Because many facilities, including Core Oncology Centers, do not have adequate systems for providing the type of palliative care that is designated by the medical service remuneration system,<sup>[29]</sup> we identified “differences in both the hard and soft aspects of medical care,” such as major differences among facilities regarding the standard of medical care provided and differences in equipment maintenance systems at different facilities, as factors leading to alterations in personnel and the level of medical care at various facilities. Although problems encountered by general hospitals include differences between the care they provide and the care provided by Core Oncology Centers, the problems of Core Oncology Centers include their lack of concern about the gap between the care they provide and the care provided by general hospitals.<sup>[30]</sup> Consequently, the problem of differences in the medical care provided by different facilities, such as public hospitals and Core Oncology Centers, has arisen. The required roles of Core Oncology Centers include providing support with multidisciplinary medical care to medical facilities in a region and helping to establish and maintain systems of cooperation among hospitals and between hospitals and clinics. Measures: Therefore, to ensure uniform access to cancer care, it is necessary to ensure that there is an agreement among medical facilities on a daily basis so that all services can remain responsive to the medical needs faced by each facility.

#### 4.3.3 Disparities in the quality of medical care standards and difficulties in maintaining and improving quality

**Problem:** Although Core Oncology Centers need to organize the palliative care teams in all other hospitals, only 34.0% have records of payment for palliative care, indicating disparities in the practices followed by different Core Oncology Centers.<sup>[29]</sup> This specifies that the phenomenon of “personnel shortages [because of] people avoiding outlying regions,” also expressed as one of the opinions in this study, leads to regional differences among hospitals throughout Japan. Because “quality is not maintained in line with requirements,” Core Oncology Centers throughout Japan find it tough to satisfy all designated requirements,<sup>[17]</sup> resulting in disparities in satisfaction of requirements at different centers, which in turn lead to shortages in personnel and equipment. Measures: Moreover, when we identified “difficulties in maintaining and improving equipment to improve the quality of medical care,” for all types of facilities to be able to improve the quality of their health care without cre-

ating budgetary problems, it is necessary to possess better equipment and facilities and appropriate medical specialists on staff. To ensure uniform access, flexibility is needed in each medical facility rather than placing importance only on the designated requirements.

#### **4.3.4 Disproportionate distribution of palliative care wards and insufficient regional cooperation**

**Problem:** Presently, creating a uniform system of multidisciplinary cancer treatment and including the end stage of the disease are problems faced by the medical field in Japan.<sup>[17]</sup>

A survey of facilities revealed that while palliative care is provided at multiple medical facilities, they are unable to provide hospice or palliative care wards at or hospice, thereby failing to fulfill the wishes of patients with cancer. Seemingly, it is challenging for hospitals to simultaneously provide individualized care and operate palliative care wards that meet all patients' needs.<sup>[31]</sup> Despite opinions such as "the overall number of palliative care wards is low" and "the equipment and facilities available at palliative care wards differ from region to region and, as a result, there is no uniform access," there are disparities in the availability of palliative care wards in places such as Hokkaido and Chiba Prefecture, parts of which lie within the Tokyo Metropolitan Area.<sup>[32,33]</sup> **Measures:** Therefore, further efforts are required to promote an increased understanding of these issues through incentives, such as proposals to increase the remuneration for medical care provided by palliative care wards, which would create opportunities to establish palliative care wards in remote areas and, in turn, contribute to ensuring uniform access.

**Problem:** With regard to insufficient regional cooperation, the Basic Plan to Promote Cancer Control Program aims to ensure a system of supportive at-home care and strengthen the medical, welfare, and nursing care network that provides at-home care to patients with cancer.<sup>[34]</sup> In 2012, the cancer-related mortality rate at home in all prefectures of Japan accounted for 12.8% of all deaths, indicating a low rate from a global perspective.<sup>[35]</sup> The reasons for this low rate in Japan include delays in establishing an at-home care system and anxiety felt by patients and their family members. Only few physicians in the country are specialized to provide at-home palliative care, which is another issue. Although there are registered at-home treatment support clinics, only a few provide the services.<sup>[36]</sup> Presumably, these circumstances lead to opinions such as "Although a system that allows cancer patients in outlying regions to receive the same care at home as they would in a hospital, no such system currently exists" and "Because care has always been provided mainly in hospitals, the at-home care system lags behind the in-hospital care system." The efficient use of financial resources available in regional areas to provide remuneration for medical services

rendered by facilities directly involved in cancer care remains a pressing issue.<sup>[31]</sup> **Measures:** Therefore, to increase the number of physicians capable of providing at-home care, it is necessary to consider increasing the remuneration paid for medical care in outlying regions. Reportedly, clinics lacking beds receive lower payments for at-home cancer care than those that possess beds. Therefore, increasing the medical remuneration paid to facilities without beds must be considered as another way to ensure uniform access to cancer care.

#### **4.4 Factors related to lack of understanding on the part of administrators and organizations**

##### **4.4.1 Insufficient understanding on the part of administrators and organizations as a whole**

**Measures:** The term "cancer board" is often used for facilities that examine cases. For example, at the University of Tokyo Hospital, cancer care problems involving the entire hospital are reviewed in detail by a Cancer Board headed by the Hospital Director and the Executive Division of the hospital.<sup>[37]</sup> Acute care hospitals focus on their Departments of Emergency Care; however, because cancer care issues are not prioritized, hospital administrators and the organization as a whole are unable to fully understand cancer care problems or act upon them. Because medical practitioners have instilled ideas and activities outlined in the hospital policies, hospital administrators need to create environments wherein the hospital as a whole is more aware of cancer-related issues.

##### **4.4.2 Insufficient guarantee of the status of and insufficient utilization of human resources**

**Measures:** Our survey opined that "OCNSs are a resource for hospitals, but are limited in outlying regions." Many medical facilities without OCNSs<sup>[38]</sup> suggest that an increased understanding of OCNSs by administrators and hospital organizations would contribute to ensuring uniform access to cancer care and overcome barriers among medical facilities.

#### **4.5 Factors related to public policy**

##### **4.5.1 Insufficient qualitative parameters for ensuring uniform access**

**Problem:** The nursing training program related to cancer care managed by the Japanese Nursing Association aims to provide nurses with a wealth of knowledge about palliative care and nursing care to understand cancer care "from diagnosis to palliative care." As of 2015, 96% nurses at Core Oncology Centers had attended the program. The future goals of the program include "brush-up" education for graduate nurses to help them disseminate their palliative care knowledge for the greater good in the society and to develop and encourage the use of care depending on patient-specific

characteristics of different regions.<sup>[36]</sup> However, one of the identified codes in this study was “I would like the presence of more venues where nurses can utilize their unique functions. I wish there were a type of nursing education designed for this purpose.” There is, however, nothing in the program that addresses the issue of remuneration for care, such as medical care payments.

Reportedly, many medical facilities are unable to provide sufficient education and training to their staff because of the differences in the perceptions of different specialized staff members, including nurses.<sup>[31]</sup> Unlike physicians whose remuneration increase with their experience, nurses who are mainly paid a “cancer patient guidance and management fee” receive an additional payment only on a one-time outpatient/inpatient basis for each case handled. Furthermore, nurses cannot expect payment for consultation and other types of medical services that are not included as part of the nursing duties and do not qualify for remuneration.<sup>[39]</sup> With insufficient additional medical payments, nurses may not only feel that their work is undervalued but also be deprived of a sense of accomplishment. This leads to the following comment on our survey, “The remuneration system does not reflect the actual work of nurses.” Therefore, it is urgent that the Japanese Nursing Association gathers and analyzes data on the daily activities performed by nurses. Measures: Furthermore, it would better if the government creates a new remuneration system for nursing activities. These initiatives would improve nurses’ motivation and create opportunities to frame policies that would narrow the differences in nurses’ perceptions and lead to a better understanding of nurses on the part of hospital organizations.

#### 4.6 Deficiencies in the development of public policy and difficulty applying public policies

**Problem:** Over the years, although the number of Core Oncology Centers has increased in Japan, the creation of a medical system comprising facilities and equipment to improve the patients’ QOL has lagged. Many institutions believe that the financial support they receive in support of these activities is woefully inadequate;<sup>[31]</sup> in fact, more than 90% Core Oncology Centers complain that the subsidies they receive are insufficient. Subsidies from both regional and national sources equal to 20 million yen, but some regional governments are unable to pay their full share of burden. This leads to a situation in which the actual amount of money available totals 6 million yen.<sup>[17,40]</sup> Therefore, the “negative image of the designated requirements and remuneration system at medical facilities,” for example, “Although there is a strong impression that there is a structure in place to satisfy the requirements, in fact, this structure lacks sufficient content,”

and “the bar set by the new requirements is too high,” implies that hospital services are not tailored to the characteristics of the area in which they are located owing to the constraints of the designated requirements they must follow.<sup>[31]</sup> Measures: By reforming the policies that not only subsidies but also the remuneration received by medical practitioners is reflected in the actual treatment and care they provide on a daily basis to adequately reward hospitals and medical practitioners for their services, medical practitioners would feel optimistic about the public policies and be inclined toward self-improvement. Therefore, flexible public policies adapted to the regional characteristics and aligned with actual conditions in clinical settings are critical to ensure uniform access.

##### 4.6.1 Insufficient cooperation between national/local governments and medical facilities

**Problem:** It is essential to frame public policies according to the needs of those providing and receiving medical care.<sup>[6,10]</sup> Because there is a “lack of opportunities to sense that public policy is working [for nurses],” it is possible that the needs of those providing and receiving medical care in Japan do not reach the national level where these public policies are created. The results of our survey “Public policy is not in line with conditions in clinical settings” and “The designated requirements are too strict and are not in line with conditions in clinical settings” indicate that medical practitioners have no chance to express their ideas and opinions to those in the national government. The goal of uniform access is to satisfy the medical needs of patients. The existence of Core Oncology Centers is significant only when they satisfy patients’ needs and improve QOL.<sup>[17]</sup> The priority of medical practitioners is to ascertain their patients’ needs and provide appropriate care. Measures: Therefore, it is necessary to create an interrelationship between the government and clinical settings. The belief of Core Oncology Centers that the requirements they must satisfy are too stringent<sup>[10,17]</sup> has led to the impression that the government has implemented requirements that are not unrelated to actual conditions. Although problems with facilities and personnel can be blamed for this situation, to achieve uniform access, the government must be more cognizant of the real conditions faced by medical facilities by, for example, conducting surveys to assess actual clinical settings.

**Problem:** Extrapolation of the code, “The national government provides no incentives to regional and local governments regarding palliative care,” indicates that the lack of awareness of the situation faced by patients and their family members is a barrier to the provision of palliative care. Perhaps, subsidies provided by the government could increase the number of medical facilities providing cancer care, lead-

ing more people to gain knowledge about cancer treatment and palliative care. Since 2014, the government has been attempting to improve the functionality of Core Oncology Centers through a new cancer treatment system wherein Core Oncology Centers can directly inform the Ministry of Health, Labour and Welfare about their facility.<sup>[2]</sup> However, the Ministry receives this information through authorities in the prefectural governments where the center is located. Initially presumed to enhance cooperation between Core Oncology Centers and their regional governments, it actually dwindles the direct link between the centers and the national government. Measures: Hence, there should also be a system by which the centers can directly inform the federal government of their situation.

#### **4.6.2 Misunderstanding by the general public of cancer care and insufficient supply of information to the general public**

**Problem:** Despite an education program in place, a 2014 opinion poll indicated that only 34.3% of the population was “well aware” of palliative care and > 50% either only knew the word or “did not know anything about palliative care”.<sup>[41]</sup> Many patients with cancer are elderly who lack computer and technical skills and therefore cannot obtain information about palliative care from the internet. Presumably, medical facilities also do not sufficiently inform the public about palliative care and cancer treatment. Measures: Therefore, if, rather than the national government, hospitals—which are closely related to patients—were to organize classes and conduct public relations campaigns on cancer, it is more likely to eliminate misunderstandings about palliative care. Therefore, a system needs to be created by which hospitals can effectively provide information to the general public through cooperation with organizations that are already doing this job, such as the Orange Balloon Project and the Japan Breast Cancer Pink Ribbon Movement.

#### **4.7 Relationships among factors**

“Factors related to the education and training systems” affect “factors related to medical specialties and workforce” because there are disparities in the types of personnel in different regions. Although the distribution of medical specialists at Core Oncology Centers is stipulated by the Basic Plan to Promote Cancer Control Program, the staff training systems are not able to keep up with the demand. This inevitably leads to the differences in “Factors related to the standard of medical care,” which in turn cause the disparities in cancer care observed across the country. Moreover, the influential factor expressed as “factors related to an insufficient understanding on the part of administrators and organizations” has a powerful influence on this situation. An

inadequate understanding of cancer care on the part of officials and organizations as a whole creates a situation wherein medical specialists are not appropriately utilized at medical facilities.

“Factors related to the standard of medical care” and “factors related to public policy” affect each other, but insufficient public policy development by the national government leads to lower medical standards, causing a detachment between the established policies and the actual conditions in clinical settings, which in turn leads to dissatisfaction with the government.

Of the five factors, improvements in “factors related to the education and training systems,” “factors related to an insufficient understanding on the part of administrators and organizations,” and “factors related to public policy” would lead to the realization of uniform access to cancer care (see Figure 1).

This study was a survey of the inhibitory factors of uniform access to cancer care according to the statements made by OCNSs who work in cancer-related settings. Hence, it would be difficult to apply the conclusions of this study to all medical practitioners. Furthermore, because the detailed responses were biased toward opinions regarding palliative care, designated requirements, and Core Oncology Centers, their application to efforts ensuring uniform access to all types of cancer treatment would be challenging.

## **5. CONCLUSION**

This study suggests that to ensure uniform access to cancer care, any improvement plan must include improvements to the education and training systems, promote the understanding of administrators and organizations, such as medical facilities, and ensure that the public policies are according to actual conditions in clinical settings. The fact that there are facilities with non-OCNSs as staff members suggests that it is necessary for organizations to understand the importance of efforts that close barriers between different medical facilities. In future, it is essential for medical services and the national government to cooperate in their re-examination of the public policies related to cancer.

Therefore, the current healthcare system relies on hospitals and related organizations to provide support for the education and training of medical professionals in Japan regarding cancer care; however, these hospitals and organizations may be reluctant to provide financial support for the same to avoid a budget deficit. However, as a result of progress made in public policy, such as the establishment of the Cancer Control Act, instead of depending solely on the hospitals and related organizations for solutions to problems such as differ-

ences in the numbers of medical professionals on the basis of facilities and regions, the national government is required to create a system that provides support to “each individual.” There are also regional differences in the organizations that provide education and training to medical professionals, which should be seen as an important issue. Therefore, the government needs to aim for the future improvement of the domestic medical standards instead of seeking short-term profit. These efforts may lead to an increase in the number of medical professionals and the creation of higher quality guidelines as a result of discussions regarding these problems. These developments may then result in the ability to provide equal medical care to all patients. The results of this study also showed that it is essential for those in managerial positions to understand the various medical professionals working in their organizations. As many medical specialists demonstrate their abilities, it can result in professional recognition. Conversely, it also depends on medical specialists improving their skills on a daily basis. Therefore, it is essential that medical professionals exchange information and participate in training programs outside the confines of the hospitals where they work. Cancer patients are subject to the treatment they receive at hospitals located where they live, that is, their care may vary depending on which hospital they go to for treatment. Therefore, general hospitals that do not have the facilities required to provide cancer treatment have no choice but to depend upon core hospitals that have the latest medical equipment. Both hospitals can cover each other by collaborations between professionals of different organizations and compensate for deficiencies in different medical services payment schedules. If the national government keeps in mind the patients suffering from cancer, they

would be able to create a more feasible system.

Recently, Japan has put a great deal of effort into at-home care, but the profitability issue needs to be resolved to create a preferential remuneration system for patients receiving at-home care and pay more attention to the education and training of medical practitioners specialized in delivering at-home care. Moreover, for correcting the misunderstanding among the Japanese public that palliative care is simply another term for terminal care, increased support needs to be provided to NPOs so that community residents can gain appropriate knowledge regarding palliative care from other residents in their local communities.

Therefore, it is necessary for us to discuss the national medical policies focusing on each individual member of society.

The U.K. follows the system of the General Practitioner laid down by the “NHS”. In addition, in the United States of America, local inhabitants are examined by Primary Care Physicians. However, the Japanese medical system is freely accessible. The patient can choose the required facilities from all domestic hospitals. The “free access” system produces the factor which has been clarified in this study. Therefore, the country should undertake comprehensive arguments in the future.

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#### CONFLICTS OF INTEREST DISCLOSURE

The authors declare that there is no conflict of interest.

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