

Center for Cancer Control and Information Services

Preface

The Center for Cancer Control and Information Services (CIS) is a nationally funded program established in 2006, as an essential part of the National Cancer Center's (NCC) extramural activities. The Division of Health Services Research and the Division of Cancer Survivorship were newly established in April 2013. The former aims to establish an evaluation system for health systems and health policy performance in cancer care in Japan and the latter aims to enhance the quality of life of people with cancer and their caregivers, and to promote social awareness in Japan about cancer survivorship issues. Then the CIS consisted of six Divisions.

The mission statement of the CIS is as follows: "The Center for Cancer Control and Information Services provides information needed to promote comprehensive and systematic cancer control program in Japan." In collaboration with designated cancer care hospitals, the Japanese Ministry of Health Labour and Welfare and other relevant Ministries, the Center plays a central role to plan, manage and evaluate nation-wide cancer control programs, through promotion of specialized, multidisciplinary and comprehensive cancer research, coordination of training and information dissemination, and support of prevention, diagnosis, treatment of cancer, rehabilitation from cancer and the continuing care of cancer patients and their families.

One of our key mandates is to provide all patients and their dear ones, the means to access comprehensive cancer-related information at the point of need, and with appropriate context including websites such as "ganjoho.jp-www.ganjoho.jp". Followed by publications for patients with cancer diagnosis, the revision of a cancer information handbook for patients with cancer named "Guidebook for Cancer Patients", and publication for workers named "Prescription for Cancer Survivors" represented an important step in this direction.

The CIS promotes the standardization of hospital-based cancer registries in designated cancer care hospitals and population-based cancer registries in prefectures. The data are collected from both hospital-based and population-based cancer registries, analyzed to calculate accurate cancer statistics and disseminated throughout Japan. Furthermore, The CIS has continuously made strong efforts to develop a reliable cancer surveillance system in Japan, which is stated as a key element in the Cancer Control Act. In the year 2013, the Act on Promotion of Cancer Registries was enacted as well.

The CIS also builds partnership with Designated Cancer Care Hospitals to support all health-allied professionals concerned with cancer control in Japan with the pathology consultation service, radiology consultation service, cancer image reference database, radiotherapy case service and promotion of medical education programs for cancer control

The CIS aims to research activities and advocacies based on the following four pillars: Monitoring and Evaluation, Development and Research of Practical Programs, Public Education and Information Services, and Promoting Policy and Networking.

Fumihiko Wakao, M.D.
Director, Center for Cancer Control and Information Services

Organization

President:

Tomomitsu Hotta

Director:

Fumihiko Wakao

Division of Cancer Information Service

Chief: Tomoko Takayama

Information Development Research Section

Communication Research Section

Evaluation Research Section

Division of Surveillance

Chief: Hiroshi Nishimoto

Epidemiology and Statistics Section

Population-based Cancer Registry Section

Hospital-based Cancer Registry Section

Cancer Care Statistics Section

Economics Section

Division of Medical Support and Partnership

Chief: Masashi Kato

Medical Support and Partnership Section

Pathology Consultation Section

Radiology Consultation Service

Outreach Radiation Oncology and Physics Section

Cancer Control Educations and Trainings Section

Division of Cancer Survivorship Research

Chief: Miyako Takahashi

Division of Health Services Research

Chief: Takahiro Higashi

Division of Tobacco Policy Research

Chief: Yumiko Mochizuki-Kobayashi

Activities of the Divisions

DIVISION OF CANCER INFORMATION SERVICE

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Introduction

The mission of the Cancer Information Services is to provide credible information about cancer. In the National Cancer Information Network, the Cancer Information Services plays an important role in disseminating cancer-related information directly to our audiences, including patients and their families, the public at large, healthcare professionals, policy makers and researchers. Our dissemination channels also include the 397 designated cancer care hospitals and their respective cancer information and support teams. Currently, multi-channel cancer information services are provided through the internet, brochures, lectures, and public meetings. One of our key mandates, is to provide all patients and their loved ones, with the means to access comprehensive cancer-related information at the point of need, and with appropriate context including websites such as “ganjoho.jp” and “www.ganjoho.jp”. Followed by publications for patients with a cancer diagnosis, the revision of a cancer information handbook for patients with cancer named “Guidebook for Cancer Patients”, and a publication for workers entitled “Prescription for Cancer Survivors” represented an important step in this direction. In order to disseminate information effectively to the general public, we concluded agreements for the spread of information with health insurance companies and pharmaceutical companies.

Line of service

Cancer Information Development Section

The Cancer Information Development Section has exerted efforts to provide reliable, evidence-based cancer information to patients, their families, citizens, healthcare professionals, researchers, and policy makers. Evidence databases such as clinical practice guidelines and research findings are continuously sourced, assessed, and edited, ensuring that the information is presented in a manner consistent with how the users digest and process the information. As part of continually providing reliable information in an easily understood format, treatment guidelines are evaluated using the AGREE

II (Appraisal of Guidelines for Research & Evaluation II) instrument and are accumulated as evidence repositories. Information is disseminated through various media formats, including the website “Cancer Information Service <http://ganjoho.jp>”, a wide range of patient education brochures, flyers and handbooks that contain comprehensive cancer information to help empower patients and families throughout the continuum of cancer survivorship. The Section also helps direct health care providers by providing access to an extensive library of articles on cancer treatment and supportive information that have undergone CIS peer reviews, as well as other cancer information sources that are of interest to health care professionals.

Communication Research Section

In order to disseminate and utilize reliable cancer information, the Communication Research Section is in charge of supporting the smooth operation of cancer information services and of encouraging the collaboration among relevant stakeholders, such as the Cancer Information & Support Centers (CISCs) in designated cancer hospitals (397 locations around the nation), support groups, and prefectural government units responsible for planning and managing their respective regional cancer programs. The Section handles broader scale training workshops and region block forums for CISC's staff, in addition to seminars for the public and local health care workers. The section also prepares and manages collaborative work with the “Patient-civil panel” which consists of 100 supporters with a variety of experiences with cancer and different regional backgrounds from throughout Japan, and provides mutual educational forums for media professionals.

Research activities

Cancer Information Development Section

To ensure timely dissemination of accurate and pertinent information on cancer, and to more effectively support decision-making by patients, their families and the general public, we conduct extensive surveys to better gauge what type of

information is needed, how it needs to be delivered in order to make a timely impact, and which stakeholders in the community need to be part of the delivery/dissemination network. Increasingly, we are also involving regional community stakeholders, patients and care providers, to help compile more a regionally pertinent set of information, in the effort to improve our community outreach efforts.

Communication Research Section

To overcome the disparities of cancer related

information all over Japan and to contribute to building better cancer information and support systems, this Section conducts a portfolio of research in wide ranging areas such as the identification of underserved populations, building a cross functional network of community care providers, defining the activities of cancer information centers, developing innovative educational programs and training methods that help accelerate best practice adoption among cancer information counselors.

DIVISION OF SURVEILLANCE

Hiroshi Nishimoto, Kota Katanoda, Tomohiro Matsuda, Akiko Shibata, Koichi B. Ishikawa, Ayako Matsuda, Yoshiko Emori, Kaori Nakano

Introduction

The Division of Surveillance is in charge of providing credible cancer statistics to patients and their families, to the public, to healthcare professionals, to policy makers and to researchers. The Division also collects accurate and useful information on cancer statistics at the national level. We promote the standardization of hospital-based cancer registries in designated cancer care hospitals and population-based cancer registries in prefectures. The data are collected from both hospital-based and population-based cancer registries, analyzed to calculate accurate cancer statistics and disseminated throughout Japan. A newly incorporated economics section will augment the epidemiologic data with economic information crucial for formulation of future policy.

Routine activities

Population-based Cancer Registries

The division has continuously exerted efforts to develop a reliable cancer surveillance system in Japan, which is stated as a key element in the Cancer Control Act. In the year 2013, the Act on Promotion of Cancer Registry was enacted as well. The Division supports all these 47 registries, by disseminating up-to-date information through websites and mailing lists; by setting up a Q&A service; by holding a one day seminar in May for administrative officers in charge of cancer control who were new to their post, a total of 36 participants; and by organizing 2-day educational workshops for cancer registrars and administrative officers, a total of 198 participants attending the one in December. The Division also provided site visiting as part of training for the Standard Database System (SDS), for promoting the protection of personal information, and for cancer registry start-up preparation. This activity supported a total of 17 prefectures in 2013. Standardization of the population-based cancer registry has steadily advanced: 45 registries out of 47 use the standard registry items. Forty registries had introduced the SDS as of January 2014. Introduction is in progress in one registry and the other one is planning to introduce it in 2014. The self-check software on security control in cancer registration, and security

educational materials for new workers were updated and provided by the division.

Hospital-based Cancer Registries

Since a hospital-based cancer registry (HCR) is essential to evaluate cancer care in each hospital and also to achieve high completeness of population-based cancer registries, it should be established urgently for cancer control. The Division plays an important role as a driving force for the standardization and quality improvement of HCRs, which has been performed at 397 designated cancer care hospitals (DCCHs) and over 300 other hospitals in 2013. In collaboration with other relevant parties, the division develops data standards for HCR, modifies datasets, and distributes the standardized software "Hos-CanR PLUS", which is used in about 800 hospitals. In 2013, individual records for 584,120 cancer cases diagnosed in 2011 were collected from 395 DCCHs. To improve the data quality, the Division devised an education program for cancer registrars through holding three one-week-long workshops for experts in Tokyo per year and 2-day workshops for beginners twice a year at 12 cities in which about 1,500 registrars participated. Furthermore, the Division performed site visits to 33 DCCHs in 2013.

Cancer Statistics

The Division is in charge of providing information on cancer statistics. The updated data of cancer mortality, incidence, survival, and prevalence, the secular trends of cancer mortality and incidence, and the framework of cancer control in Japan have been published both on the web site and in a book titled "Cancer Statistics in Japan".

Research activities

Population-based Cancer Registries

The national cancer incidences in 2009 and 2010 were estimated based on the data from 37 and 31 cancer registries, respectively. The prefectures that have met the data quality standards have increased since last year. The incidence data were then analyzed in detail by cancer site. The study results were published in an international journal. The cancer incidence data have been used in a couple of research analyses; the results are presented at

conferences both in Japan and abroad.

Table 1. Population-based Cancer Registries from Prefectural Registries

Year of Diagnosis	Prefectures	Number of New Cancer Cases
2009	37 (32 for estimation)	775,601
2010	31 (28 for estimation)	805,236

Cancer Patients Data from Hospital-based Cancer Registries at Designated Cancer Care Hospitals

Table 2. Year of Diagnosis Applied Hospitals Number of New Cancer Cases

Year of Diagnosis	Applied Hospitals	Number of New Cancer Cases
2010	387	548,979
2011	395	584,120

Cancer Statistics

International comparisons of cancer burden

List of papers published in 2013 Journal

- Chihara D, Ito H, Matsuda T, Katanoda K, Shibata A, Taniguchi S, Utsunomiya A, Sobue T, Matsuo K. Association between decreasing trend in the mortality of adult T-cell leukemia/lymphoma and allogeneic hematopoietic stem cell transplants in Japan: analysis of Japanese vital statistics and Japan Society for Hematopoietic Cell Transplantation (JSHCT). *Blood Cancer J*, 3:e159, 2013
- Katanoda K, Matsuda T, Matsuda A, Shibata A, Nishino Y, Fujita M, Soda M, Ioka A, Sobue T, Nishimoto H. An updated report of the trends in cancer incidence and mortality in Japan. *Jpn J Clin Oncol*, 43:492-507, 2013
- Katanoda K, Shibata A. Worldwide burden of cancer death below the age of 40 extrapolated from the WHO mortality database. *Jpn J Clin Oncol*, 43:584-585, 2013
- Kunisawa S, Morishima T, Ukawa N, Ikai H, Otsubo T, Ishikawa KB, Yokota C, Minematsu K, Fushimi K, Imanaka Y. Association of geographical factors with administration of tissue plasminogen activator for acute ischemic stroke. *J Am Heart Assoc*, 2:e000336, 2013
- Kuwabara K, Fushimi K, Matsuda S, Ishikawa KB, Horiguchi H, Fujimori K. Association of early post-procedure hemodynamic management with the outcomes of subarachnoid hemorrhage patients. *J Neurol*, 260:820-831, 2013
- Kuwabara K, Hagiwara A, Matsuda S, Fushimi K, Ishikawa KB, Horiguchi H, Fujimori K. A community-based comparison of trauma patient outcomes between D- and L-lactate fluids. *Am J Emerg Med*, 31:206-214, 2013
- Machii R, Saika K. Burden of cancer in Asia extrapolated from the WHO mortality database. *Jpn J Clin Oncol*, 43:218, 2013
- Machii R, Saika K. Estimated Disability-Adjusted Life Year (DALY) in Asia in GLOBOCAN 2008. *Jpn J Clin Oncol*, 43:846-847, 2013
- Matsuda A, Katanoda K. Estimated disability-adjusted life year (DALY) in all cancers in GLOBOCAN 2008, in Asia by the country. *Jpn J Clin Oncol*, 43:943-944, 2013
- Matsuda A, Katanoda K. Five-year relative survival rate of lung cancer in the USA, Europe and Japan. *Jpn J Clin Oncol*, 43:1287-1288, 2013
- Matsuda A, Machii R. Worldwide relative burden of cancer death in 2008 extrapolated from the WHO mortality database. *Jpn J Clin Oncol*, 43:102, 2013
- Matsuda A, Matsuda T. Burden of cancer death in Asia below the age of 40 extrapolated from the WHO mortality database. *Jpn J Clin Oncol*, 43:682-683, 2013
- Matsuda A, Matsuda T, Shibata A, Katanoda K, Sobue T, Nishimoto H. Cancer incidence and incidence rates in Japan in 2007: a study of 21 population-based cancer registries for the Monitoring of Cancer Incidence in Japan (MCIJ) project. *Jpn J Clin Oncol*, 43:328-336, 2013
- Matsuda T, Matsuda A. Burden of cancer incidence below the age of 40 in Asia 2002 extrapolated from the Cancer Incidence in Five Continents Vol. IX. *Jpn J Clin Oncol*, 43:449-450, 2013
- Matsuda T, Saika K. The 5-year relative survival rate of stomach cancer in the USA, Europe and Japan. *Jpn J Clin Oncol*, 43:1157-1158, 2013
- Miyazaki Y, Hayashi K, Mizunuma H, Lee JS, Katanoda K, Imazeki S, Suzuki S. Smoking habits in relation to reproductive events among Japanese women: findings of the Japanese Nurses' Health Study. *Prev Med*, 57:729-731, 2013
- Nakahara S, Katanoda K, Ichikawa M. Onset of a declining trend in fatal motor vehicle crashes involving drunk-driving in Japan. *J Epidemiol*, 23:195-204, 2013
- Saika K, Machii R. Five-year relative survival rate of cancer in the USA, Europe and Japan. *Jpn J Clin Oncol*, 43:1053-1054, 2013
- Saika K, Matsuda T. Estimated disability-adjusted life year (DALY) in Japan in GLOBOCAN 2008. *Jpn J Clin Oncol*, 43:768-769, 2013
- Saika K, Yako-Suketomo H. Worldwide burden of cancer incidence below the age of 40 in 2002 extrapolated from the Cancer Incidence in Five Continents Vol. IX. *Jpn J Clin Oncol*, 43:343-344, 2013
- Shimizu S, Ishikawa KB, Ikeda S, Fushimi K. How does prescription of generic drugs spread out?: data mining and visualization by using prescription data from acute care hospitals nationwide. *Value Health*, 16:A460-A461, 2013

and survival rate were conducted based on the WHO mortality, GLOBOCAN, and cancer registry databases. An updated trend analysis of cancer incidence and mortality in Japan was conducted. A trend analysis was also conducted for adult T-cell leukemia/lymphoma. Tobacco control situations were analyzed in three East Asian countries: Japan, China and the Republic of Korea.

Economic studies on cancer care

In order to construct a nation-wide database of inpatient and outpatient clinical practice, we started to collect DPC-survey compliant data from over 1,000 hospitals. These data are used to identify cancer care process, accessibility and costs. Initial findings on the use of pharmaceuticals related to chemotherapy will be published in early 2014. Findings from this database and other information related to the utilization of services will be linked with population estimates to form future forecasts of supply and demand in cancer care.

DIVISION OF MEDICAL SUPPORT AND PARTNERSHIP

Masashi Kato, Hiroaki Onaya, Jun Itami, Ryoji Kushima, Yoshinori Makino, Miki Hosoya, Toshiyuki Minemura, Yoko Nakazawa, Takashi Hanada, Yuki Aono, Tadakazu Shimoda, Kanako Kono, Yuko Ogo, Saran Yoshida, Satoshi Ishikura, Hiroko Suketomo, Megumi Fukuda, Ritsuko Chinda, Yuri Yamauchi, Hiromi Nakamura, Toshiko Sakaguchi, Shiho Hirai, Hiroyo Ohchi, Chisako Ito, Erina Sasaki

Introduction

The Division builds partnership with Designated Cancer Care Hospitals to support all health-allied professionals concerned with for cancer control in Japan. The Medical Support and Partnership Section (MSPS) plays a unique role in suggesting the cancer control policy in Japan. The Pathology Consultation Section (PCS) strives to perform human pathology research based on histology of tumor cells and tumor-stromal cells to improve the diagnostic pathology of tumors. The Diagnostic Radiology Section (DRS) provides a consultation service and a cancer image reference database (NCC-CIR). A radiology consultation service is aimed at the improvement of the quality of diagnosis based on medical images. The NCC-CIR is a web-based reference database system of images of neoplasms for physicians, radiologists, and pathologists, providing medical diagnostic images and information together with the pathology. The Outreach Radiation Oncology and Physics Section (ORPS) provides the following support programs for designated regional cancer centers and institutions participating in clinical trials. The Cancer Control Education and Training Section (CCET) plays a central role in the planning, management and evaluation of specialized and multidisciplinary training programs for physicians and other health professionals as trainers of each designated cancer care hospital, to promote a comprehensive and systematic cancer control program in Japan.

Routine activities

A. Networking among Designated Cancer Care Hospitals

The MSPS formed a network among the designated cancer care hospitals to build partnership for cancer control in Japan. The designated cancer care hospitals are important partners with the NCC to promote comprehensive cancer control in Japan. The Palliative Care Committee was established as a subsidiary organization of the Designated Cancer Care Hospitals Liaison-Council in this year.

B. Pathology consultation service

The pathology slides of lesions arising in various organs have been submitted from clients. Eighty-four consultant pathologists who are specialists in various fields are registered, and one pathologist who was assigned as consultant examined the slides and rapidly sent back the report and opinion to each client. Most of the clients expressed satisfaction with the contents of the report and this consultation system. We started the selection of typical and educational consultation cases from accumulated archival slides and the construction of a referential database.

C. Radiology consultation service

Ninety-three consultation reports have been put together for requests mainly from the Kanto and Kyushu region. Hepato-biliary-pancreatic, musculoskeletal, and lung lesions were the common subjects. Consultation with a specialist was the most frequent reason (37.9%) for consultation. The client radiologists have evaluated 314 (91.0%) of the 345 consultation reports as being useful for the presence of clinical impact on the final radiological diagnoses.

D. NCC-CIR

The average number of effective accesses to this site was almost the same as that in 2012, about 100000 per month. Cases with cancers who underwent interventional radiology (n=11), head and neck cancers (n=8), musculoskeletal malignancies (n=7), lung cancers (n=5), and other cancers have been published, resulting in the total provision of 284 cases.

E. Radiotherapy case service

Mailed dosimetry and on-site dosimetry were performed in 45 institutions and 11 institutions, respectively. All data of the institutions were within the permissible limit. In clinical trials, radiotherapy case reviews were performed in 39 institutions.

F. Promotion of medical education programs for cancer control

The CCET provides and evaluates various

oncology professional training programs about up-to-date information on early detection, diagnosis, treatment, care, cancer research, clinical trials and cancer statistics for physicians, nurses, pharmacists, cancer information (CI) specialists, technologists and cancer registrars. The CCET also provides multidisciplinary training programs for Palliative Care Teams and Chemotherapy Teams. (Table 1)

Research activities

Evaluate changes in Palliative Care with the Cancer Control Program

To evaluate the changes of palliative care induced by the Basic Plan to Promote Cancer Control Program in Japan, evaluation indicators are developed, and an interview survey is conducted with cancer patients and healthcare professionals.

Cancer Control Program Evaluation Workshop for Government Employees

The MSPS conducted a workshop for government employees on 'How to evaluate your prefecture's cancer control programs.' It was funded by the Japanese Ministry of Health, Labour and Welfare and was used by 33 prefectures in Japan that deal with cancer control programs.

Trend of pathology consultation services

Activity of the section was introduced in "Pathology and Clinical Medicine" which is the most popular journal for Japanese pathologists.

Develop and use of a teleradiology system

The section is investigating methods to improve the way how we can send and receive digital imaging files more easily and more quickly using a teleradiology system.

Develop the IMRT quality control support program

The Outreach Radiation Oncology and Physics Section were developing enforcement of the on-site dosimetry regarding the output dose of Intensity Modulated Radiotherapy (IMRT) in 4 institutions (designated regional cancer centers).

Clinical trials

In the Japan Clinical Oncology Group (JCOG1015, JCOG1208) and Japanese Radiation Oncology Study Group (JROSG12-1), the Outreach Radiation Oncology and Physics Section performed the on-site dosimetry regarding the output dose of IMRT in 5 institutions.

Table 1. Training programs conducted during April 2012 - March 2013

Category of Education and Training program	Titles of Education and Training program	Number of participants
Oncology nursing education	Continuing education and development of oncology nursing workshop for trainers	63
	Continuing education and development of oncology nursing workshop for trainers-Follow up	33
	Oncology nursing seminar for trainers	245
	Oncology nursing on the job training for trainers	6
CI specialist education	CI Specialist Education Program -Basic course 1	665
	CI Specialist Education Program -Basic course 2	664
	CI Specialist Education Program -Basic course 3	321
	CI Specialist Education Program for trainers	59
	CI Specialist Education Program for trainers-Follow up	47
Hospital-based cancer registrar training	Training program for instructors of hospital-based cancer registrars	21
	Continuous training program for instructors of hospital-based cancer registrars	2
	Supplementary training program for instructors of hospital-based cancer registrars	78
	Basic training program for hospital-based cancer registrars	1249
	Supplementary training program for hospital-based cancer registrars of basic course completion	715
	Advanced training program for hospital-based cancer registrars	157
	Site Visiting program on hospital-based cancer registries in national cancer center hospital	74
Training for population-based cancer registrars and administrative officers in charge of cancer control	Basic training programs on population-based cancer registry for population-based cancer registrars in charge of cancer control	76
	Basic training programs on population-based cancer registry for administrative officers in charge of cancer control	211
Technologist education	Trainer training for oncologic radiology technologists	17
	Trainer training for oncologic laboratory medical technologists	5
Pharmacist education	Seminar for pharmacists of dispensing neoplastic agents to be trainers	56
	On the job training for pharmacists of dispensing neoplastic agents to be trainers	23
Palliative care physicians education	Palliative care education meeting for trainers	56
Psycho-oncologists education	Psycho-oncology education meeting for trainers	33
Palliative care team education	Palliative care team workshops for consultation-Basic course	70
Chemotherapy Team education	Chemotherapy Team workshops to introduce a new drug safety	64
Total		5010

List of papers published in 2013 Journal

- Morita T, Sato K, Miyashita M, Akiyama M, Kato M, Kawagoe S, Kinoshita H, Shirahige Y, Yamakawa S, Yamada M, Eguchi K. Exploring the perceived changes and the reasons why expected outcomes were not obtained in individual levels in a successful regional palliative care intervention trial: an analysis for interpretations. *Support Care Cancer*, 21:3393-3402, 2013
- Morita T, Miyashita M, Yamagishi A, Akiyama M, Akizuki N, Hirai K, Imura C, Kato M, Kizawa Y, Shirahige Y, Yamaguchi T, Eguchi K. Effects of a programme of interventions on regional comprehensive palliative care for patients with cancer: a mixed-methods study. *Lancet Oncol*, 14:638-646, 2013
- Komura K, Yamagishi A, Akizuki N, Kawagoe S, Kato M, Morita T, Eguchi K. Patient-perceived usefulness and practical obstacles of patient-held records for cancer patients in Japan: OPTIM study. *Palliat Med*, 27:179-184, 2013
- Yamamoto R, Kizawa Y, Nakazawa Y, Morita T. The palliative care knowledge questionnaire for PEACE: reliability and validity of an instrument to measure palliative care knowledge among physicians. *J Palliat Med*, 16:1423-1428, 2013
- Sato Y, Watanabe H, Sone M, Onaya H, Sakamoto N, Osuga K, Takahashi M, Arai Y. Tumor response evaluation criteria for HCC (hepatocellular carcinoma) treated using TACE (transcatheter arterial chemoembolization): RECIST (response evaluation criteria in solid tumors) version 1.1 and mRECIST (modified RECIST): JIVROSG-0602. *Ups J Med Sci*, 118:16-22, 2013

DIVISION OF CANCER SURVIVORSHIP RESEARCH

Miyako Takahashi, Makiko Tomita, Yuko Furuya, Kyoko Onozawa

Introduction

The Division of Cancer Survivorship was newly established in April 2013. Our mission is to enhance the quality of life of people with cancer and their caregivers, and to promote social awareness in Japan about cancer survivorship issues.

As for academic research, we deal with various psychosocial issues associated with the cancer experience such as employment, interpersonal relationships, sexuality and fertility, prejudice against cancer, and life-style modifications. In particular, we examine the influence of the Japanese socio-cultural background on living with and beyond cancer, and try to propose countermeasures based on the research findings.

As for activities to promote social awareness toward cancer survivorship, we plan and implement educational programs for the general public as well as healthcare providers.

Routine activities

Education programs to promote social awareness of cancer survivorship

We plan and implement two lecture series, “Community Center Café” and “Gotochi (Local) Café”, which are open to the public. These café programs, which are held in a relaxed atmosphere with a cup of tea or coffee, provide participants an opportunity to learn about cancer survivorship issues as well as exchange views among survivors, medical professionals, and the general public. The Community Center Café is held bimonthly in the Tsukishima Community Center in Chuo ward, where the National Cancer Center is located. This program consists of a lecture that takes up various cancer survivorship topics followed by a small group discussion by participants based on the lecture. The Gotochi (Local) Café has the same structure as the Community Center Cafe, but is co-sponsored by

our Division and healthcare providers in other prefectures in Japan, and focuses on high priority survivorship issues within the local community. In 2013, we held the Community Center Café three times and 150 people participated. Two Gotochi Cafés are in preparation; both are to be held in January 2014 in Okinawa and Miyagi prefectures in co-sponsorship with local healthcare providers.

Education for healthcare providers

In addition to the café programs, we conduct symposia in academic conferences and deliver lectures for healthcare providers that include oncologists, nurses, social workers, and occupational physicians. In 2013, we participated in six symposia in academic conferences, and conducted 28 invited lectures on cancer survivorship. We also delivered lectures in universities for medical and nursing students.

Research activities

Cancer and work

In order to support working cancer survivors in both the workplace setting and the hospital setting, we developed and evaluated pilot intervention programs targeting occupational health staff and medical social workers (MSW), respectively. Also, we conducted surveys with occupational physicians (OPs) to collect good practices about sharing a patient’s medical information between oncologists and OPs.

Sexuality, life-style modification, parental cancer

In preparation for a multi-center survivorship survey with gynecological cancer patients, we conducted literature review and developed a questionnaire that includes items regarding sexual changes, life-style modification after having cancer, and communication with children.

List of papers published in 2013 Journal

1. Takeda Y, Morio K, Snell L, Otaki J, Takahashi M, Kai I. Characteristic profiles among students and junior doctors with specific career preferences. *BMC Med Educ*, 13:125-135, 2013
2. Inoue M, Takahashi M, Kai I. Impact of communicative and critical health literacy on understanding of diabetes care and self-efficacy in diabetes management: a cross-sectional study of primary care in Japan. *BMC Fam Pract*, 14:40-48, 2013

DIVISION OF HEALTH SERVICES RESEARCH

Takahiro Higashi, Momoko Iwamoto, Kota Tanaka, Izumi Kamiya, Ayako Okuyama, Fumiaki Nakamura, Yoichiro Tsukada, Rei Goto, Kaoru Konno

Introduction

In order to establish an evaluation system for health systems and health policy performance in cancer care in Japan, the Division of Health Services Research primarily focused on the following three research projects in 2013.

Research activities

Establishing a clinical database by linking hospital-based cancer registry and DPC / insurance claims data

As a first step in monitoring the quality of cancer care and ensuring equitable access to care in Japan, the division developed a large clinical database that linked hospital-based cancer registry data with DPC / insurance claims data obtained from cancer care hospitals throughout Japan. The Division distributed free encryption software designed to support different file formats used by various hospitals, which allowed multiple data sources to be synthesized smoothly into a single database. The database contains de-identified information on all procedures, tests, and prescriptions given to patients with major cancers from over 160 hospitals across the country. The data are currently being cleaned and analyzed to measure cancer quality measures, such as the proportion of stage III colorectal cancer patients that received adjuvant chemotherapy within 8 weeks of surgery.

Defining key terminologies in cancer policy

Some words and phrases often used in cancer policy have never been clearly defined. For example, “cancer board” could imply a small meeting of surgeons, radiologists, and oncologists, or an extensive multidisciplinary conference involving nurses, pharmacists, and social workers. Even routine administrative meetings among heads of departments are sometimes referred to as cancer boards. Specialists and various stakeholders were interviewed regarding their understanding and use of key terminologies often used in cancer policy. Although a detailed consensus was not achieved in most cases, the basic concepts and underlying

definitions that were commonly shared were clarified and published into a final report.

Designing performance indicators for cancer programs

A clearly defined set of performance indicators to measure health policy performance in cancer care have never been developed in Japan. In order to develop such a system to monitor the performance of cancer programs, the Division gathered a panel of experts including clinical specialists, patient representatives, biomedical and public health researchers, cancer information experts, and policy makers. Using the Delphi method, a list of candidate performance indicators were evaluated by the panel, along with instructions to make suggestions for new indicators. The Division hopes to release these sets of performance indicators by the end of the fiscal year.

Research training and education

The Division has had a continuous flow of physicians and graduate students for research trainings throughout the year. Additionally, the Division accepted fifth year medical students from the University of Tokyo for a clerkship in Public Health.

Future prospects

The Division supports evidence-based policy-making and strives to improve the care of cancer patients in Japan by monitoring the performance of cancer policy and quality of care in cancer treatment centers across the country. In addition to the current activities, the Division is working to provide an information exchange platform for specialists and various stakeholders, designed to foster smooth communication and active exchange of ideas for cancer policy planning at the local government level. The Division will continue to endeavor to make policy recommendations that are clinically relevant and evidence-based, for various cancer control programs in Japan.

List of papers published in 2013

Journal

1. Higashi T, Nakamura F, Shimada Y, Shinkai T, Muranaka T, Kamiike W, Mekata E, Kondo K, Wada Y, Sakai H, Ohtani M, Yamaguchi T, Sugiura N, Higashide S, Haga Y, Kinoshita A, Yamamoto T, Ezaki T, Hanada S, Makita F, Sobue T, Okamura T. Quality of gastric cancer care in designated cancer care hospitals in Japan. *Int J Qual Health Care*, 25:418-428, 2013
2. Higashi T, Nakamura F, Saruki N, Sobue T. Establishing a quality measurement system for cancer care in Japan. *Jpn J Clin Oncol*, 43:225-232, 2013
3. Higashi T, Nakamura F, Saruki N, Takegami M, Hosokawa T, Fukuhara S, Nakayama T, Sobue T. Evaluation of newspaper articles for coverage of public reporting data: a case study of unadjusted cancer survival data. *Jpn J Clin Oncol*, 43:95-100, 2013
4. Nakamura F, Higashi T. Pattern of prophylaxis administration for chemotherapy-induced nausea and vomiting: an analysis of city-based health insurance data. *Int J Clin Oncol*, 18:971-976, 2013

DIVISION OF TOBACCO POLICY RESEARCH

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Introduction

The death toll attributable to tobacco use is a manmade disaster worldwide but many countries have successfully shown that it is avoidable with effective tobacco control regulations. Thus, to achieve the global standard level of tobacco policies, our missions are research activities and advocacies based on the following four pillars: Monitoring and Evaluation, Development and Research of Practical Programs, Public Education and Information Services, and Promoting Policy and Networking.

Routine and Research activities

- We developed a database for tobacco-related studies supported by government research grants. It enabled us to review intensively researcher, research outcomes and research areas and to demonstrate evidence to allow the appropriate allocation of resource and research gaps. In order to conduct rigorous monitoring of the implementation of tobacco policies, we developed a tobacco information repository which contains public information and data such as statistics, policies, studies, and activities so that experts such as administrators and researchers could have efficient access to the necessary and accurate information. By using this repository, we could analyze intensively the current trend of the tobacco epidemic in Japan.
- We conducted participatory workshops with elementary to junior high school children on tobacco with respect to cancer education. We also examined cancer patients-oriented cessation programs and quitline service programs in Japan based on expert panel discussion.
- We organized educational events at the WHO-backed World No Tobacco Day (marked on May 31) and Science Agora of Japan Science and Technology Agency (JST) to educate people on tobacco and cancer issues and also contributed to policy and program development by governments, schools and NGO/NPOs. We marked February 27 to celebrate the WHO Framework Convention on Tobacco Control (FCTC) and broadcast a Ustream program. Essential documents which are internationally available were intensively translated into Japanese.
- We organized a research and policy network with other National Centers to develop research areas comparable with USNIH research activities as well as policy recommendations to the government. As a part of the Tobacco Free Committee of Japan Science Council, we made an urgent policy recommendation to stop the epidemic of smokeless tobacco use. As a part of the Tobacco Risk Assessment Committee of Ministry of Health, Labour and Welfare, we submitted a thorough review on tobacco products from the viewpoint of regulatory science. Policy advocacy for research and regulatory framework was needed.