Teaching Global Asia

A Lecture Series to Understand Malaysian Case Surviving Cancer in Asia: Cross-boundary Cancer Studies, The University of Tokyo

Shigeto Sonoda
Norie Kawahara

GAS
Global
Asian Studies

Booklet GAS

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東京大学
THE UNIVERSITY OF TOKYO

Preface

Global Asian Studies (GAS) program in IASA started in 2022 to promote an “inside-out” approach, which respects the agency of local scholarship to determine what should be studied, while engaging with global audience. This program has several missions, one of which is to think of the teaching of global Asia.

This time, I’m very happy to announce the publication of the booklet titled “Teaching Global Asia” which was designed and coordinated by Dr. Norie Kawahara who was a project associate professor at IASA. Dr. Kawahara initiated a lecture series titled Surviving Cancer in Asia in 2011 with late Prof. Hideyuki Akaza. As her attempts were very innovative, trying to combine experts of a variety of disciplines to think of the importance of cancer prevention in global scale but in concretely local context, I encouraged her to edit this booklet to let more readers know about what she is doing in education.

Dr. Kawahara is now managing BEAUTY (Bringing Education and Understanding To You) and Health Project to tackle some difficult issues on the cancer prevention in multi-ethnic Malaysia. The lectures offered in the class were structured so that students can understand the Malaysian case and think of the possible solutions.

Though the number of registered students in the class was not so large, I hope this small but innovative educational attempts will evoke people’s interests in understanding Asia from interdisciplinary approaches from within.

Shigeto Sonoda
Chair of GAS Program

Cross-boundary Cancer Studies within the Context of Global Asian Studies

Norie Kawahara

Since its inception in 2011 as a lecture series within the Japan-Asia Studies Program, Cross-boundary Cancer Studies has maintained its focus on deciphering the current situation across Asia, based on the shared challenge posed to humanity by cancer. The Japan-Asia Studies Program represented the University of Tokyo's university-wide collaboration in Asian studies, and was also recognized as a lecture series that posed questions relating to how Japan has approached Asia to date, and how it should best interact with Asia in the future. Although the program unfortunately concluded in academic year 2020, the questions it raised and tackled over the course of a decade remain valid today, as the path that Japan took in the postwar years and how it has interacted with Asian neighbors continue to provide lessons today. Taking on the legacy of the Japan-Asia Studies Program, a new lecture series has been devised under the leadership of Professor Shigeto Sonoda, and we are most appreciative to have the opportunity to be able to publish the lecture transcripts as a Global Asian Studies report.

Asia has been described as being "near and yet so far" from Japan, and wars of the past remain embedded in Asia's present. It has been said that there are two trends in Japan's international cooperation during the postwar period. One is the "international line," which aims at international public interest in line with predominantly Western perspectives, and the other is the "domestic line," which has its origins in postwar reparations. The Cross-boundary Cancer Studies network traces its own origins to the Asian Cancer Registry and Information Network meeting held in Nanjing in 2007 (the "Nanjing Conference"), and this network has continued to this day, following in large part the "domestic line." https://www.nature.com/articles/450772c#about-the-journal

In 2022, war revisited Europe for yet another time in its history, and the future of Japan's postwar relationship with China, which has long been questioned and considered, and which Cross-Boundary Cancer Studies has dedicated much effort to nurturing, is now facing an uncertain future. Could we really dare to hope that by facing together the vexatious challenge of cancer we could transcend past hatred and suspicion and work together to share issues that are common to all Asian societies, thus enabling pan-Asian solidarity? Can we create wisdom sufficient enough to overcome the foolishness and original sin of human existence through Cross-boundary Cancer Studies?

It is with such hopes lodged in our hearts that since 2011 we have been conducting interdisciplinary cancer research based on the late Dr. Akaza's firmly-held belief that "cancer is a mirror."

Cross-boundary Cancer Studies is a lecture series designed to decipher the present state of Asia through both the uniqueness and universality inherent in cases of cancer, but it has proved difficult in practice to share questions and devise a system through which to provide the lectures during the course of the academic term. The advantage of interdisciplinary research is that examining multiple areas at once may result in new discoveries that individual researchers had previously been unaware of. However, when collecting and deciphering cases based on such diverse perspectives and specialties, we nonetheless felt the necessity for some kind of unifying baseline perspective that would undergird our research and study.

Moreover, even within Asia, as medical care has become ever more sophisticated and the values being pursued are increasingly converging with those of the West, we struggled with the question of how to ascertain a real picture of Asia that would take into account both the high degree of regional disparities, coupled with the high universality of cancer medicine.

It was with these issues and considerations in mind that from this year, the program shifted focus to throw a spotlight on Malaysia, based on the BEAUTY (Bringing Education And Understanding To You) Program, an actual program supported by the Sustainability Division of Astellas Pharma Inc. https://www.astellas.com/en/sustainability/program-in-malaysia

In cooperation with the National Cancer Society Malaysia (NCSM), the goal of the learning process was to provide the participants with both opportunities to learn and to make their own suggestions regarding the BEAUTY Program.

The BEAUTY Program is targeting more than one million Malaysian residents and involves various processes, including the establishment of a database for cancer education, a cancer prevention registry portal, and community participation sessions for raising cancer awareness in the local community. These processes are focused primarily on beauty salons and barber shops as community touchpoints. This community-based approach has real potential to go beyond a narrow circle of researchers and truly involve local communities, accumulating the combined power not only of medical science, but also of humanities and social sciences, to decipher and better understand the current state of Malaysia, and, more broadly, a fast-changing Asia.

Forty years ago, around the time when the Look East Policy began in Malaysia, I was a student at Waseda University. It was during my time as a student working for the Japan-side partner organization of the ASEAN Council of Japan Alumni (ASCOJA) that I first started to be involved with Malaysia. Later, I made a promise with Mr. Tanaka Nichijun, a Buddhist monk who was a prison chaplain for Class-BC war criminal, to 'do our utmost to overcome the tragic legacy of

war. That is what has driven me to continue the activities of the Asian Cancer Forum. Having become deeply involved in the BEAUTY Program in Malaysia, I can now appreciate that neither of the abovementioned traditional approaches to international cooperation are truly applicable to the current reality. I understand most keenly that facing the realities of 21st-century Asia means more than Japan simply trying to atone for a past war, or imposing Western logic in the course of providing poverty relief. We must find an approach that is imbued with an entirely Asian perspective.

Seeking as it does to realize a world in which no-one is left behind, the concept of Universal Health Coverage (UHC) could also be perceived as a riddle: in a world in which the progress of science has blessed us with increased longevity, but at the expense of increased cancer incidence, how can humanity survive with limited and finite resources, while also giving free rein to human ambitions and aspirations?

Acknowledgements

We would like to thank the people who provided support for this lecture series, with their rich and valuable insights, comments and examples.

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Lecture No. 1

Introduction: Significance of interdisciplinary approaches to UHC for cancer in Asia

Shigeto Sonoda

Professor, Institute for Advanced Studies on Asia (IASA), The University of Tokyo

(1) Introduction to the lecture series

One of the reasons Prof. Sonoda accepted the offer to host this lecture series on Surviving Cancer in Asia is that he is currently chairing the International Grant Program of the Toyota Foundation (since 2019). Applicants for this grant program have to submit a proposal to promote dialogue across disciplines and across national boundaries. The successful applicants for the current year have recently been announced and cover a broad range of areas. The reality facing research today is that professors have very limited opportunities to encourage or introduce students to work with other disciplines, particularly across international borders. Just like the complexity of initiatives being implemented under the Toyota Foundation program, the challenge of cancer in Asia is multifaceted and has diverse aspects that change from country to country and region to region.

Prof. Sonoda explained that the aim of this class is to provide students with a variety of knowledge about what has been done to prevent, cure, and care for cancer in Asia through the collaboration with Union for International Cancer Control (UICC) Asia Regional Office (ARO). This class will be held in an omnibus style, inviting many guest speakers including medical doctors, experts on cancer studies, etc. Students will get to understand that cancer is a “social disease” that has many dimensions to be considered in Asia. During the program the case of Malaysia will be explored and Malaysia-Japan collaboration will be discussed, focusing on the BEAUTY (Bringing Education and Understanding To You) and Health Project.

The issue of cancer has multiple dimensions that need to be addressed, and it is precisely this multidisciplinary style of lecture course that will help to grow understanding about the issues and identify potential areas for collaboration.

Dr. Norie Kawahara is the coordinator for this class. She is the representative of the Asia Cancer Forum and is the Japan-side leader of the BEAUTY and Health Project, which is being supported by Astellas Pharma.

(2) Introducing the BEAUTY and Health Program

Dr. Kawahara noted that Malaysia and Japan are celebrating the 40th anniversary of the Look East Policy (LEP) this year. Cancer collaboration is also greatly influenced by the power of diplomacy.

The BEAUTY and Health Project is designed to communicate the negative topic of cancer in a way that is more accessible to the public. In addition to gaining knowledge and awareness about cancer, the smartphone app that will be used under this project aims to increase the cancer screening rate and promote early detection and treatment. It aims to fuse the digital with the human.

The Asia Cancer Forum is fortunate to have IT partners in both Japan and Malaysia and with them it is hoped to create a social networking platform to create UHC for cancer and ensure that no-one is left behind.

(3) Structure of the lecture series

Prof. Sonoda introduced the structure of the class, noting that some lectures would be provided live via Zoom, while others would be provided on demand. Question and answer sessions would also be held during each lecture. The series runs from October 2022 to January 2023 and it is planned to invite many experts preeminent in their fields. In particular, lecturers from Malaysia will be joining the class on a number of occasions, giving students the opportunity to take a deep dive into the realities of cancer care in Malaysia, including the practical application of cancer care policies in the field in Malaysia, as introduced by representatives of the National Cancer Society of Malaysia (NCSM).

Class evaluation will comprise of attendance and short reports submitted (40%) and the final presentation and report (60%). The theme of the final report is to make comments and suggestions for the BEAUTY and Health Project for further development.

Students explained their reasons for auditing the lecture series. Some of these reasons include the rising awareness of cancer as a disease in Asia, and an interest in understanding how Japan and Malaysia are approaching cancer care. Students from Asia expressed an interest in understanding about the costs of cancer and accessibility of affordable care. Other students noted that they had previously audited the lecture series and it had proved extremely interesting and instructive. Other students explained their interest in the BEAUTY & Health Project in Malaysia from the perspective of health economics.

Prof. Sonoda asked students to evaluate the following statement: “Many areas of research including cancer studies are said to be in need of interdisciplinary approaches.”

Students noted that historically fields have been in very specifically defined areas, which is also important from the perspective of advancing knowledge. However, as research becomes more advanced the boundaries that have been set historically can limit the scope of research and therefore interdisciplinarity is necessary in order to improve applicability and long-term impact. An interdisciplinary approach, however, requires an effective team of people from different disciplines, which can be challenging. People with a certain set of expert knowledge tend to be very focused on their own specialty and it can be difficult to get people to interact with people beyond their own fields. Other students noted that interacting with people in certain specialized fields can be difficult due to a lack of expert knowledge, but with tolerance and mutual explanation and understanding it is possible to advance interdisciplinary approaches. Other students stressed the importance of interdisciplinary approaches in today’s world, particularly in such areas as public health. The global COVID-19 pandemic was cited as an area where interdisciplinary collaboration has been imperative, bringing together medical aspects (epidemiology) with IT aspects and other areas. Whereas IT engineers are capable of analyzing data, they don’t have the expertise to interpret the results, which is why the input of medical experts is also critical. Another student noted the importance of interactions and sharing information, acknowledging also that it is important to find the right person and facilitate connections among people.

(4) History of the Surviving Cancer in Asia lecture series and the initiatives of Prof. Hideyuki Akaza

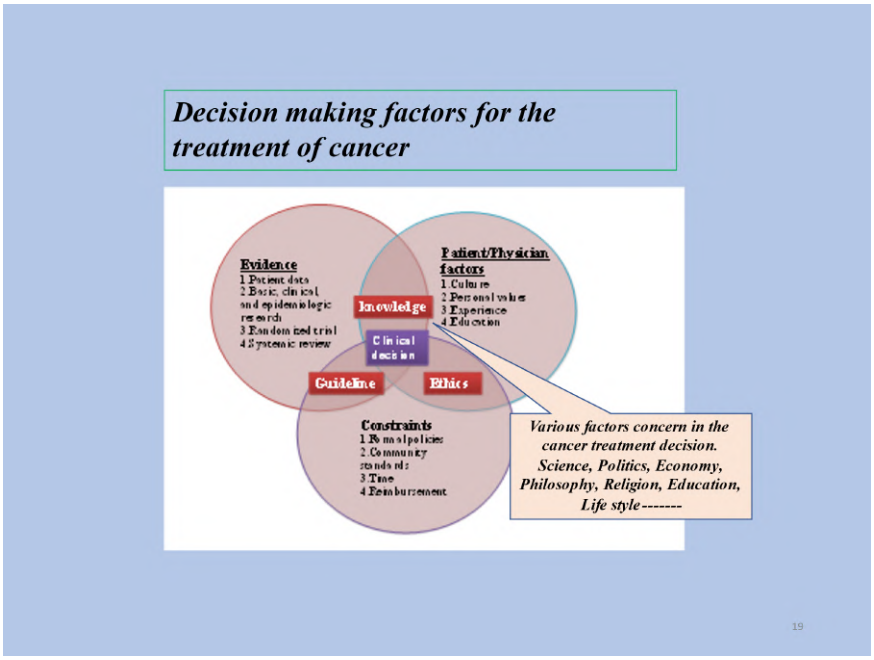
According to Prof. Sonoda, The late Prof. Hideyuki Akaza was the main organizer of the Surviving Cancer in Asia lecture series from 2013 to 2021. His main concept was “Cancer as a Mirror,” or something that reflects social reality. He tried to use the lens of cancer to look at many aspects of society. The combination of Prof. Akaza, an expert in prostate cancer and Dr. Kawahara, an expert in humanities, was very unique and facilitated the formulation of the lecture series with its cross-disciplinary focus. Both Prof. Akaza and Dr. Kawahara shared a strong aspiration to advocate a cross-disciplinary approach and cultivate young talent.

Prof. Akaza used the metaphor of “cancer as a mirror.” By this he meant that the

cancer of individual persons often mirrors the culture of a country. Secondly, the figures on the mirror may not always the same. Prof. Akaza stressed the importance of learning how to see the right figures on the mirror. In other words, he wanted to tell students to use the mirror in an appropriate way. A further message of Prof. Akaza's metaphor is to understand what lies behind the mirror as the key to understanding the world and improving cancer medicine. It was these imperatives that led Prof. Akaza to propose the "Surviving Cancer in Asia" lecture series as a cross-disciplinary course.

Prof. Akaza highlighted the decision-making factors for the treatment of cancer, bringing together knowledge, ethics and guidelines to come to a clinical decision. What made him different from other clinical doctors is that he looked at the concept of a clinical decision in a much broader way.

Figure 1: Decision-making factors for the treatment of cancer



Prof. Akaza sought to go beyond exclusively clinical-oriented decisions, including such constraining factors as formal policies, community standards, time and reimbursement of medical costs. He stressed that various factors are involved in cancer treatment decisions, including science, politics, economics, philosophy, religion, education, and lifestyle factors. Prof. Akaza urged medical doctors to take an interest in and try to learn more about these other factors.

It was this desire that led to the creation of Cross-boundary Cancer Studies. Prof. Akaza invited a diverse range of speakers and activated discussions from various angles. Professor. Sonoda provided his evaluation of the lecture series to date and future challenges.

He noted that previously there had been few opportunities for scholars of different disciplines to discuss “cancer as a mirror,” which became a seedbed for new research and collaboration.

In addition, a pioneering program at the University of Tokyo to teach “Global Asian Studies” also sought to position cancer as a common issue Asia is now facing.

However, through the years it has proven difficult to manage the cross-disciplinary class. Very few speakers have seemed to realize in detail the common issues/challenges to be tackled and the incentives for social scientists to join in what superficially at least appears to be an issue in the field of science.

Another significant challenge experienced by the lecture series to date has been the lack of an international collaborative network. This year’s lecture series seeks to address this challenge for the first time by engaging in joint lectures with Malaysia.

(5) Why is collaboration needed?

Prof. Sonoda mentioned that collaboration in any discipline is essential, particularly in medical research, because one researcher cannot acquire all data alone. Furthermore, one researcher cannot be expected to cover all aspects of a phenomenon. Finally, one researcher cannot effectively describe the whole picture relating to that phenomenon. In the case of this lecture series, it will likely be the case that researchers in Malaysia have detailed knowledge about the situation in their own country, but may not be so knowledgeable about Japan. It is such deficiencies that the lecture series seeks to address.

However, it is also important for any researcher to find pointers for new ideas and innovation. Some researchers try to create new areas of research by joining interdisciplinary teams and finding new research questions. Through collaboration with scholars from different disciplines, researchers can find solutions to issues which should be addressed by interdisciplinary means. Paradoxically, marginal questions from the eyes of single disciplines can become core questions in an interdisciplinary approach.

Collaboration presents various difficulties. The first challenge is that each research

has their own research interests and it takes time to adjust them. Also, integrating the findings of each research will not necessarily produce the expected results. Another very practical problem is that it is difficult to find research partners, Prof. Sonoda said.

(6) UHC in Malaysia and the road forward

Even in terms of the concept of the UHC there are subtle differences among countries and organizations. The WHO stipulates that UHC means that "all people have access to the health services they need, when and where they need them, without financial hardship." However, depending on the levels of medical treatment, economics and finance, education, public policy and engineering the interpretation of the UHC concept may differ. Different countries face different realities and possess different ideas. Moving across disciplines and across international borders presents daunting challenges for researchers, but also eye-opening opportunities.

The issue of cancer and how to survive it in Asia is an extremely complex and thought- provoking topic. Prof. Sonoda concluded his talk by saying that it is hoped that the lectures in this year's series will provide interesting insights and suggest new ways forward.

Lecture No. 2

Where is the road to realization of UHC leading for cancer in Malaysia?

Murallitharan M.

Managing Director, National Cancer Society Malaysia (NCSM)

(1) Introduction to the lecture

Dr. Kawahara introduced Dr. M Murallitharan, noting that as Managing Director of National Cancer Society Malaysia (NCSM) he is leading efforts relating to the BEAUTY and Health Project in Malaysia. Dr. Murallitharan previously worked as a journalist and so has a different perspective to a purely medical background. Dr. Akaza, the founder of this lecture series, once said that "cancer is a mirror that reflects society," and it is to be hoped that Dr. Murallitharan will help everyone to understand the current status of cancer in Malaysia.

(2) Overview of cancer in Malaysia

Malaysia is an upper-middle income country, and as with most countries of such a level society is starting to age. As the population ages and become more economically comfortable the issue of non-communicable diseases (NCDs) starts to become more apparent, of which cancer is a notable example. Like other NCDs there are a lot of aspects to cancer that go beyond clinical issues, which can be very challenging and problematic when seeking to care for cancer patients. This is why, within the scope of cancer, NCSM has stopped using the term "patients" and sometimes, depending on the perspective, starts calling them "survivors." For a long time the term "survivors" was given to mean people who had completed treatment, but now all people are termed "survivors" from the first day that they are diagnosed. Another term used is "people living with cancer," and it does not just refer to patients, but also their family members, close companions and caregivers. This term tries to capture the depth of impact that cancer has on the overall population. It is not merely a clinical disease, and that is what makes it different from other conditions, and it imposes major social and economic impacts. Cancer also have behavioral and cultural impacts. Cancer is therefore a very complex disease with far-reaching implications.

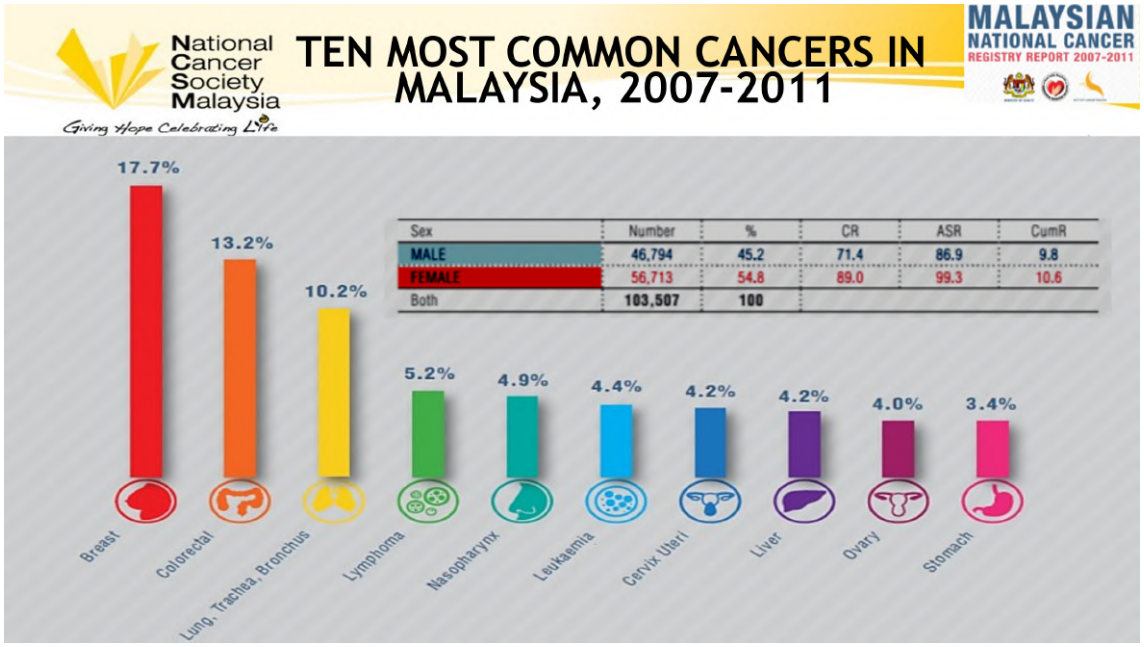
It is very interesting that the University of Tokyo has been exploring for many years through this lecture series the different holistic aspects that enable us to approach cancer

in a different manner to a purely clinical approach.

In Malaysia the most prevalent cancer is breast cancer, accounting for 17.7% of all diagnosed cancers. Female cancers account for 54.8% of all diagnosed cancers, which reflects the prevalence of breast cancer and also the tendency for male cancers to be underdiagnosed. Males tend to only come and seek treatment when cancer is at a later stage, and therefore also have poorer outcomes.

Cancers that are common to both males and females are colorectal, lung, lymphoma, nasopharynx, leukemia, liver and stomach. Generally there are approximately 20,000 new cases of cancer reported each year, which may seem low considering Malaysia's overall population, but this probably reflects a challenge relating to underreporting. In Malaysia it is still the case that a police officer can certify a death without any medical input. Anyone above 60 in Malaysia living in rural areas very often receives a death certificate with "old age" being reported as the cause of death. This has a significant impact on health statistics.

Figure 1: Prevalence of cancer in Malaysia

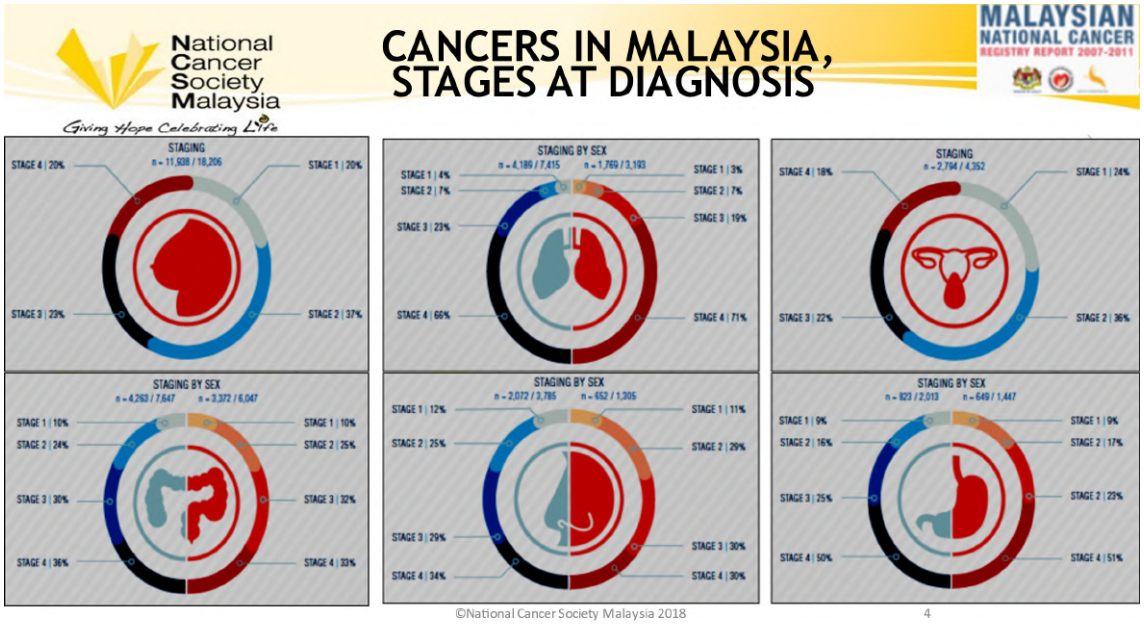


In terms of the detailed breakdown of cancers by gender in Malaysia, the most common cancers for men are colorectal and lung, and for women they are breast and colorectal. Lung cancer in males is largely driven by smoking, but there are an increasing number of non-smoking women being diagnosed with lung cancer, which may be related to the issue of second-hand smoke.

Smoking is one of the modifiable risk factors for cancer, but for women who are being exposed to second-hand smoke the risk is less modifiable, as it may be difficult to encourage male relatives to stop smoking. Whereas smoking has been denormalized as a lifestyle choice in western countries, and accordingly has led to reduced rates of lung cancer, smoking rates in Malaysia remain relatively high pending the introduction of new legislation. In actual fact Malaysia has drafted a law that would ban anyone born after 2007 from smoking, but it is currently stuck in the parliamentary system. This smoking-related bill has also become a political issue and raised discussions about the degree to which people's lives are controlled for health promotion reasons.

One area where Malaysia is doing poorly is the stage at which cancer is first diagnosed.

Figure 2: Stages at diagnosis of cancers in Malaysia

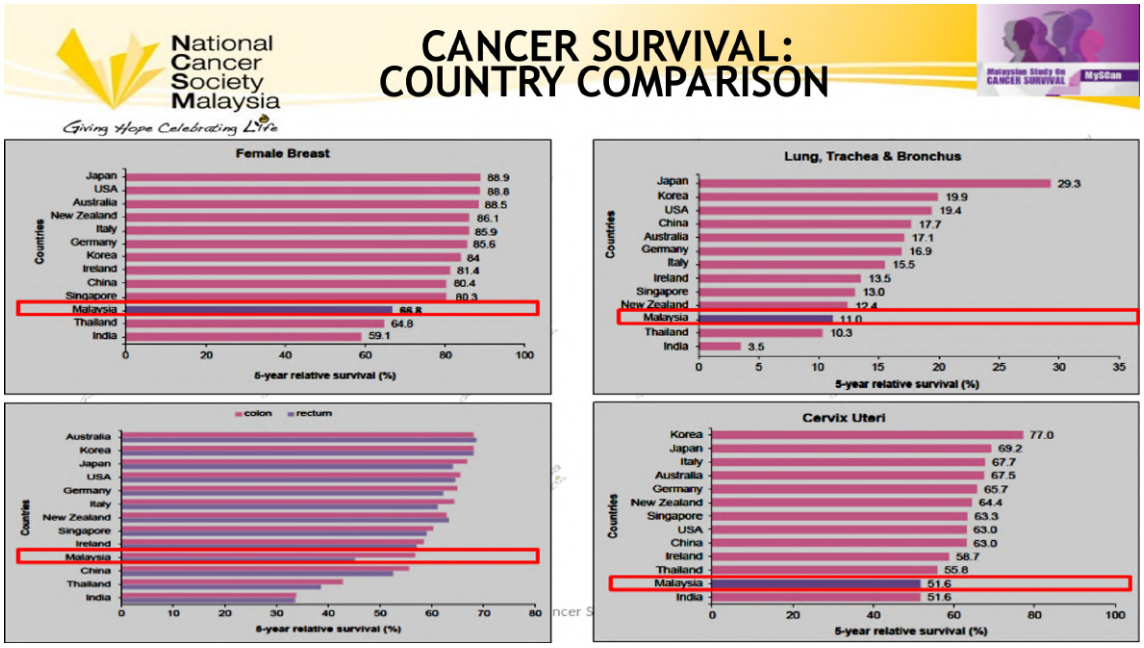


The success of cancer treatment is heavily dependent on the staging of the cancer at diagnosis, therefore late diagnosis impacts the staging, which in turn impacts survival rates.

People in stage 1 usually have a 80-90% chance of living past five years, but once diagnosed in stage 3 or 4, five-year survival drops to 20-30% or worse. In the case of breast cancer in Malaysia, approximately half of all patients are diagnosed with stage 3 or stage 4 cancer, which is difficult to treat and survivorship rates are low. A similar situation is witnessed in the staging of lung and other cancers. There are various social factors that are driving this tendency towards late diagnosis in Malaysia.

In terms of international comparisons of five-year survival rates, Malaysia ranks low due to its late detection of cancer (see Fig. 3 below). To put the reality into perspective, if you are diagnosed with lung cancer in Japan, you have a 2.5 times greater chance of surviving than in Malaysia.

Figure 3: Cancer survival, a country comparison



Some people may argue that Malaysia's lag in terms of five-year survival rates is due to facility and equipment reasons. However, increasingly the level of expertise and level of technology are similar to other countries, so this raises the question why cancer diagnosis is so low in Malaysia and what can be done to improve it.

Many of the challenges for cancer control are systemic in nature. For example, in terms of management, there is no separate funding for implementation of the National Cancer Control Plan. Also cancer is still managed separately, rather than as part of the NCD spectrum. A further challenge is that preventive services and measures to emphasize prevention are still underfunded. What is more, there is a lack of nationwide population screening programs. In public sector hospitals, there is a lack of trained sub-specialists including oncologists, due to the fact that many have moved to the private sector. There is also geographic disparity in terms of service levels provided, compounded by overloaded public sector hospitals and long waiting times. Access to innovations in treatment is also

restricted and slow and can represent the difference between life and death in some cases.

In the private sector a challenge faced by patients is financial catastrophe due to the high cost of treatment. The price of innovator drugs, particularly for those paying out-of-pocket is crippling, with long-term maintenance not covered by insurance.

Challenges for cancer control among patients included the following factors: i) low levels of cancer health literacy, ii) Late detection skills makes up more than 50% of all cases, iii) drop-out rates from treatment are high (up to 30% of cancer patients) due to the significant influence of alternative medicine practices, and iv) there is a lack of non-clinical support, in terms of psychological, rehabilitation and other psychosocial support services.

A further challenge is the non-governmental organizations (NGOs) are not effectively incorporated into the national response, with all organizations doing their own activities independently of each other, without any cohesive direction.

Discussion

Sonoda: I notice that your data included ethnic-related data, so could you perhaps say something about the ethnic distribution of cancer in Malaysia.

Murallitharan: We have a diverse population in Malaysia, with three very distinct cultural ethnicities: Malay, Chinese and Indian. The Malay population accounts for approximately 60% of the total, with ethnic Chinese accounting for approx. 25% of the total and the Indian population 8-10% of the total. According to cancer diagnosis data there are far more ethnic Chinese people being diagnosed with cancer than Malay people, despite the fact that the Malay population is the largest ethnic population in Malaysia. There are cultural factors driving this difference in the number of people diagnosed. Generally within the Chinese population people have moved from a concept of strong religious beliefs to a more pragmatic world view rather than blind faith. Along with this pragmaticism ethnic Chinese are becoming much more health conscious, because they are perceiving that this is the only life that they have. More ethnic Chinese are therefore stepping forward for regular screening, which helps in realizing early diagnosis. Ethnic Chinese people are also more inclined to follow instructions and continue with treatment.

In contrast, the Malay population is largely Muslim and there is more of a focus on spiritual aspects and preparing for the afterlife. They have a concept known as “redha,” whereby rather than going to see a doctor, they adopt a more fatalistic approach and concentrate on making peace with God. It is due to such cultural practices that cancer is very significantly underreported in the Malay population.

Sonoda: At the beginning of your talk you mentioned that male patients are generally later than females in visiting hospitals and are therefore later in being diagnosed. Another factor that may influence diagnosis is the patient’s economic level. Medical literacy is also very important, but if you try to identify the weighting of these different factors, among religious belief, ethnicity, class, and medical literacy, which do you think is the most influential in delaying people in visiting the doctor//clinic?

Murallitharan: All these factors are more closely entangled than we might expect. Looking from a very narrow medical perspective we tend to think that health literacy is everything, but there are other factors – social and economic, etc. that also have an impact.

Q: It was interesting to hear about religious and cultural beliefs and how they impact cancer screening and care. Also, the use of the term “survivor” for people from their first day of diagnosis is also an interesting concept.

Murallitharan: I helped to run a hospital on the Thai-Myanmar border, and interestingly there was a high prevalence of HIV among the young female population. Rather than focus on treatment we were trying to focus on the cause. The region borders on the Golden Triangle and workers from this region would visit the town and infect the young girls, who did not have information on practicing safe sex. There was prevalence of full-blown AIDS of about 80% and to tackle this issue we instituted a condom policy. The incentive that was provided was that if people would take a condom home to use they could buy their beer more cheaply. The hospital also worked in cooperation with the monks at local temples, utilizing people’s religious beliefs to help to impact treatment.

Q: In China the only reason that prevents people from continuing treatment is economic. In terms of the impact of religion, are there any gender differences?

Murallitharan: Rather than purely religious, the cultural impact is also significant. I have many patients who have to seek the permission of their husbands to get treatment. Another interesting phenomenon is that the wives themselves are worried about getting treatment because they are concerned that their husband might turn to other women. There are these patriarchal cultural influences that can drive decisions.

Q: Many people do not have the opportunity to improve their knowledge about early detection and treatment, and I would like to know how Malaysia is working to spread information about cancer.

Murallitharan: In some countries, like Singapore, there are health promotion organizations that specialize in promoting health information. However, in Malaysia there is very little emphasis on awareness raising, so NGOs have to take up the slack in educating people and raising awareness.

Sonoda: Today's talk has been very comprehensive, touching on political and religious influences on cancer care. Whereas some groups believe in the power of science, others turn to other doctrines or cultural norms.

Murallitharan: As you noted, COVID-19 has shown us the power of health as a political agenda. One of the big issues in Malaysian politics is that of financing for healthcare. Politics is currently in upheaval in Malaysia, but it is interesting that one of the key issues that interests the populace is how to pay for healthcare and the increasing cost of treatment and medicines. NCSM has also started to create its own election manifesto for health, setting out priorities for health in order to lobby all political parties and influence change.

Lecture No. 3

Cancer in low- and middle-income countries in the context of global health

Hajime Inoue MD, MPH, Dr.PH

Advisor; Health, Nutrition and Population Program, World Bank Group

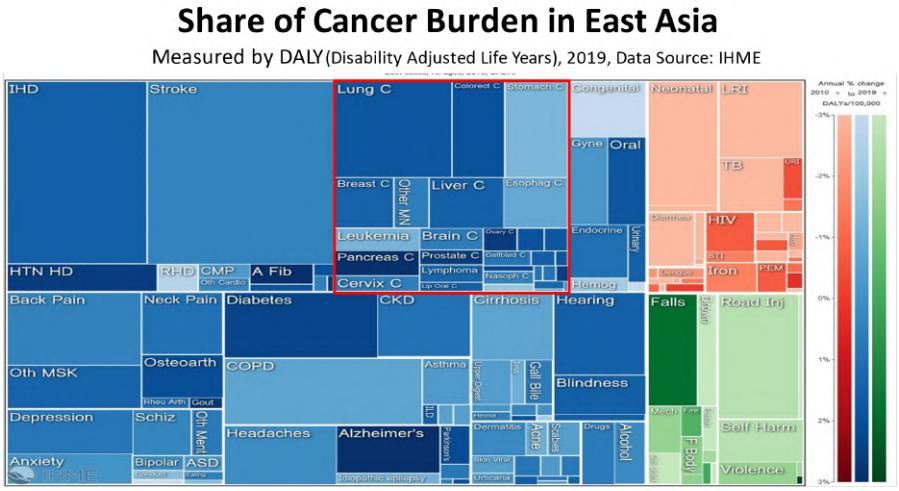
(1) Cancer burden in East Asia

This talk comprises five components: epidemiological and demographic trends in cancer in the East Asian region, the challenges of cancer treatment in low- and middle-income countries (LMIC), the need for a comprehensive approach, ways of controlling risks, and a concluding summary.

The Institute of Health Metrics Evaluation has devised a Disability Adjusted Life Years model to visualize the share of cancer burden in East Asia. In the figure the darker colors indicate that the disease or condition is increasing, whereas lighter colors indicate the number of cases is declining. As can be seen below, diseases like diabetes and Alzheimer's are increasing significantly in Asia, and various cancers are also increasing.

Highlighted in red in the figure below is the disease burden accounted for by cancer. Cancer accounts for approximately 20% of the total disease burden, and specific cancers that are increasing in prevalence include pancreatic cancer, prostate cancer, and ovarian cancer. Cancer is generally a disease of the old, namely those in their 60s, 70s and 80s.

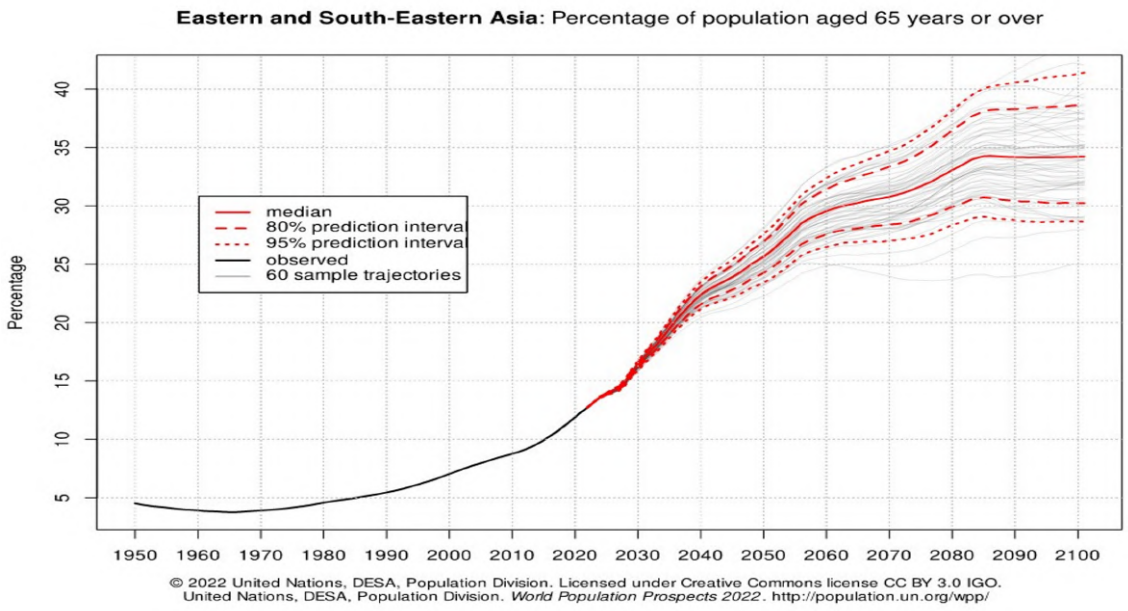
Figure 1: Share of cancer burden in East Asia (highlighted within red line)



(2) Aging populations driving increase in cancer cases

In terms of cancer mortality, every year 10 million people die from cancer, more than half of whom are in Asia. Asia is therefore the epicenter of the growing challenge presented by cancer. One of the highest risk factors for cancer is demographic risk, particularly given that the population in East and Southeast Asia is aging. When the population as a whole ages, the risk of cancer increases. The figure below shows the percentage of the population aged 65 years or older. Currently the average in the Asian region as a whole is around 13%, and in Japan it already stands at around 28 to 29%, more than double the Asian average, although the proportion of people over 65 will increase rapidly throughout the region in the coming years. In turn, this will be accompanied by an increase in cancer prevalence.

Figure 2: Percentage of population aged 65 or over (East and Southeast Asia)



As of 2020 there were approximately 20 million new cancer cases each year, with approximately 10 million people dying from cancer. The number of new cases is expected to grow rapidly, reaching approximately 32 million cases by 2040, a 50% increase over 2020 figures.

Cancer is also increasing more rapidly in low Human Development Index (HDI) countries. In terms of the projected increase in new cases between 2020 and 2040, although cases in very high HDI countries are expected to increase by approximately 30%, cases in high,

medium and low HDI countries are expected to increase significantly, over 90% in the case of low HDI countries. Most East Asian countries are categorized as either high/medium HDI countries, hence the likelihood that cancer cases will continue to rise rapidly.

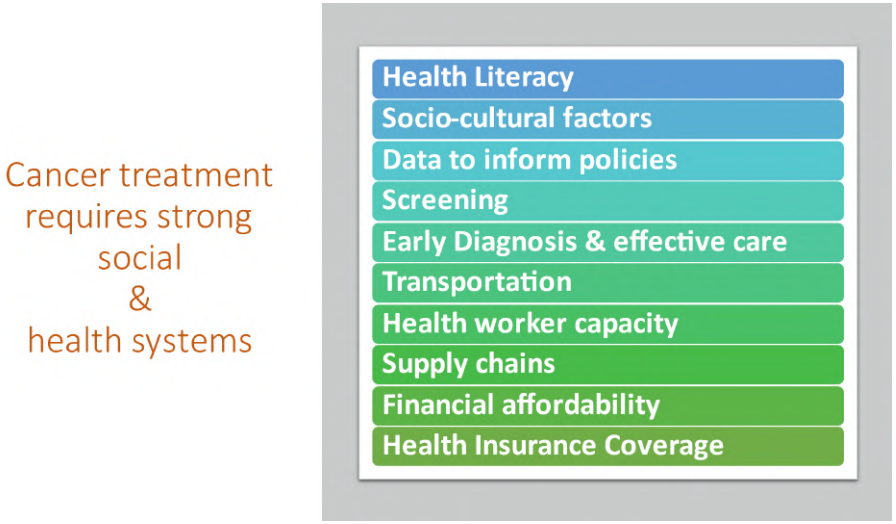
(3) Issues of access to cancer care

In terms of access to cancer care, it is a fact that treatment disparities are larger than for other diseases. Whereas comprehensive cancer treatments (surgical, radiological and chemotherapy treatments) are available in approximately 90% of cases in high income countries, in low income countries access to comprehensive coverage drops to approximately 15%. The majority of patients in low income countries therefore do not enjoy access to cancer treatment.

Cancer treatment is challenging in that it requires various elements through the care journey, including skilled specialists, heavy equipment for diagnosis and treatments, intensive care units, non-generic medicines, and cross-disciplinary work. This is in stark contrast to other increasingly prevalent diseases like diabetes, for which one medical personnel member can make a significant difference on their own, using medicines available.

Cancer treatment therefore requires strong social and health systems, in addition to capable medical professionals. Key factors that are required can be identified as follows: 1) health literacy, 2) socio-cultural factors, 3) data to inform policies, 4) screening, 5) early diagnosis and effective care, 6) transportation, 7) health worker capacity, 8) supply chains, 9) financial affordability, and 10) health insurance coverage.

Figure 3: Social and health system requirements for cancer treatment



In terms of health insurance coverage, in many medium HDI countries in East Asia universal health coverage (UHC) systems have been put in place, which offer coverage for cancer treatment to a certain extent. However, cost constraints mean that comprehensive cancer treatment remains unavailable to many people in low and middle income countries.

Ensuring access to cancer treatment is not simply about costs and facilities, or the number of physicians. It also requires a certain standard of settings for treatment and several technical aspects. For example, the World Health Organization (WHO) and International Atomic Energy Agency (IAEA) are engaging in a joint program to develop technical specifications of radiotherapy equipment for cancer treatment. These specifications aim to set standards for what equipment is needed in middle and low income countries and in so doing improve access to cancer care.

(4) Importance of a comprehensive approach to care

A comprehensive approach to cancer care is also critical in low and middle income countries as a means of proactively reducing the costs related to cancer treatment. Prevention, screening and early diagnosis are three key elements that could reasonably be expected to be implementable in cost-constrained low and middle income countries.

In terms of prevention, it is a fact that between 30 to 50% of cancers are preventable by healthy lifestyle choices. Some of the high-risk elements for cancer are obesity, alcohol, infections and tobacco. Public health workers are engaging actively in initiatives to promote prevention, with a view to decreasing the burden of cancer. Preventing cancer may also help to prevent other diseases.

In terms of infection-attributable cancer cases, including *H. pylori*, HPV, HBV, HCV and others, the total number of these cases amounts to approximately 2.2 million annually, approximately 10% of all cancer cases. Prevention of such cancers is already in theory possible using relatively low-cost measures that would be applicable even in low and middle-income settings.

In the East Asian region, the incidence rate of infection-attributable cancers is the highest in the world, with approximately 38 cases per 100,000 persons, in contrast to the worldwide average of 25 cases per 100,000 persons. Ongoing efforts to tackle infections that can cause cancer have the real potential to reduce related cancers, such as gastric cancer.

In terms of the estimated number of cancer cases attributable to alcohol, the Asian region records by far the highest number of cases, at around 430,000 cases per year. This high figure is attributable to certain ethnic factors, including the fact that a high proportion of the Asian population lacks an enzyme to digest alcohol. Alcohol control policy in Asia therefore needs to be given thought, in light of the Asian people's susceptibility to alcohol-attributable cancers.

Tobacco-attributable cancers are another challenge, and the number of smokers is estimated to be highest in middle income countries, many of which are in Asia.

(5) Conclusion

Cancer cases and deaths are increasing globally, but disproportionately in low and middle-income countries (LMIC). In addition, treatment disparities between high-income countries and LMIC are also bigger in cancer care in comparison with other kinds of disease.

Cancer treatment requires stronger social and health systems and cannot be improved by boosting the number of medical professionals alone. What is needed is a broader scope that looks beyond treatment and includes prevention. There is a long way to go before LMIC can achieve access to comprehensive cancer care, so in the interim it is important to focus more on prevention, screening and early diagnosis.

In East Asia, risks associated with infection, smoking and alcohol are higher than in other regions and this is a challenge that requires public health policy interventions.

Discussion

Sonoda: One of the key words that Dr. Inoue mentioned is the necessity for a comprehensive approach. I wonder how much this concept is appreciated in different countries, and whether LMIC share this focus on taking a comprehensive approach. Also, with regard to international collaboration, cultural factors may be difficult to deal with. How important do you think it is to promote international collaboration, particularly with a view to transform the situation for LMIC?

Inoue: With regard to the level of recognition about the importance of a comprehensive approach in LMIC, my impression is that there is not an adequate level of recognition due to several factors. One is that the most influential groups in forming cancer policy, including in Japan, is clinicians. Of course clinicians therefore have a tendency to focus

more on treatment, rather than prevention and screening. People working on prevention and screening have relatively smaller voices that clinicians. This power balance between clinical and non-clinical areas needs to be taken into account and efforts made to achieve a degree of balance.

Secondly, with regard to the need for international collaboration, it is imperative for all areas of the global health agenda, not just cancer. My impression is that the level of cooperation on cancer is less than in other areas, such as HIV or TB, for example. There is a higher level of exchange of views on these diseases compared to cancer. We are still in a suboptimal level of collaboration with regard to cancer.

Sonoda: Why do you think that there is a lower level of recognition on the need for international collaboration on cancer? Could it be a mindset that cancer is perceived as an individual's disease? Or could it be that Asia doesn't have as loud a voice as other parts of the world? What do you think are the explanations behind why cancer is paid less attention than other diseases?

Inoue: There are various factors. First, that cancer is for many East Asian countries a relatively new disease, in that it has rapidly increased over the course of a single generation, which is unique in history. Over the last 20 to 30 years the number of cancer specialists has increased rapidly in Asia in response to the growth in cancer cases. It is expected that collaboration will increase in the future as the number of specialists continues to grow.

Also, the actual level of treatment is very different among different Asian countries, which raises questions about the value of collaboration among countries. For example, in Japan all cancer care is covered under national health insurance, which guarantees access to comprehensive care. This is not the case in other Asian countries, and therefore Japan may not present an achievable goal under current circumstances. This is a challenge for collaboration. It is imperative to first work to narrow the gaps that exist among countries in Asia as an initial stepping stone to collaboration. This seminar series is one example of an initiative that is working to close the gaps in Asia.

Student: I was wondering about whether early diagnosis can be achieved in LMIC.

Inoue: Early diagnosis is certainly important and is comprised of two elements, the first of which is cancer screening, which in Japan is provided by local governments. In addition to that many people also pay for additional cancer screening. The majority of people of a certain age (over 40) have access to screening, and this is an element that LMIC need to consider introducing. There is a possibility here for Japan to share its experiences relating to screening.

One more element that is also important is cancer literacy in the general population. Even without diagnosis, in Japan when people feel that something is wrong, they recognize that there is a risk of cancer, which motivates them to visit a clinic. This readiness to visit a doctor is a result of cancer literacy among the general public.

These two areas: screening and literacy, are areas where Japan could share its experiences with other countries.

Lecture No. 4

Affordable access to care in low- and middle-income Asian countries: Some lessons from recent experience Cancer in low- and middle-income countries in the context of global health

Ajay Mahal

Professor, Nossal Institute for Global Health, The University of Melbourne

(1) Introduction to the lecture

Dr. Kawahara introduced the lecturer, Professor Ajay Mahal, He is an economist in health system and policy research and evaluation His experience will provide very useful insights in the BEAUTY and Health Project.

Professor. Mahal noted that although very often the focus can be on transferring knowledge from high income countries to low- and middle-income countries (LMICs), it should also be noted that there is much to be learned from the experiences of LMICs and how these can be applied in high income countries. Some of the more adventurous and more exciting research and initiatives are taking place in middle-income countries such as China and Indonesia.

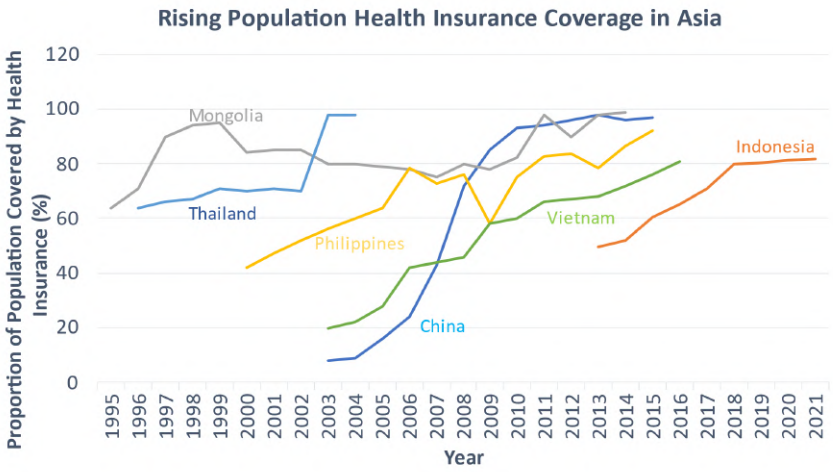
This lecture will focus on what we have learned from recent efforts to improve access to services in certain Asian countries, and what that might mean for policy going forward. The lecture will not be about cancer, but access to services more generally. Students are invited to ask questions about cancer-related issues at the end of the lecture, but with the caveat that Professor. Mahal himself is not a cancer expert. The definition used for the purposes of this lecture of “affordable access” is: “People obtain the health services they need without financial hardship and without compromising quality.”

Professor.Mahal is part of a World Bank policy advisory project looking at governments’ health spending and suggesting what the main priorities should be for the next 20 to 30 years and where resources should best be allocated.

(2) Remarkable expansion in population health insurance coverage in Asian LMICs

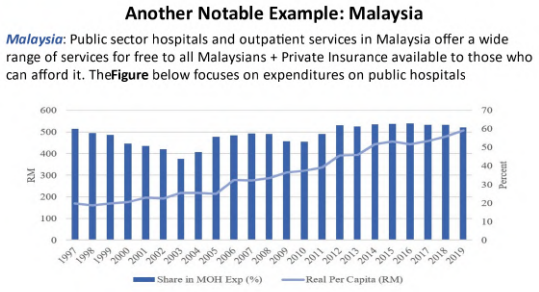
The proportion of population covered by health insurance has increased tremendously over the last 25 years, with some countries such as China seeing astonishingly rapid growth in coverage over a very short time.

Figure 1: Health insurance coverage in Asia



The speed at which this coverage has been achieved is truly unprecedented. The important thing to note is that insurance or access to services is not simply access to "formal insurance," it can also be through a highly subsidized set of services as made available by the government, the British National Health Service being one such example. There are similar examples of such systems in Asia, and Malaysia is one. Public sector hospitals and outpatient services in Malaysia offer a wide range of services for free to all Malaysians and private insurance to those who can afford it.

Figure 2: Expenditure on public hospitals in Malaysia



There has been rapid expansion in population coverage in a range of major Asian LMICs, so what are some of the lessons that can be learned from the experience of recent years?

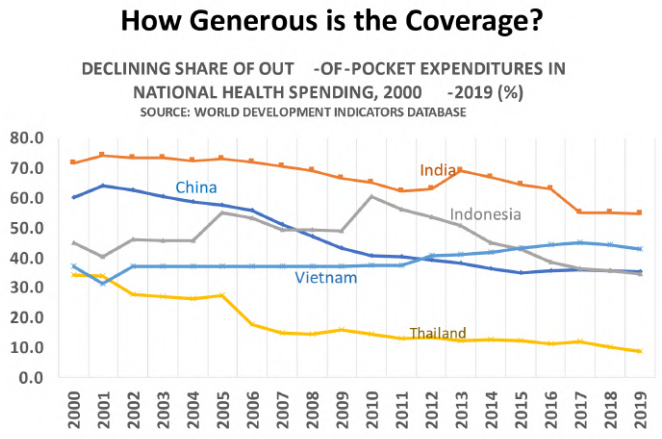
(3) Lessons from rapid rollout of health insurance coverage in Asia

The first lesson is that the high share of informal work means that income-based premiums

have not been easy to implement in LMICs in Asia. This is because it is difficult to separate poor from non-poor informal workers for purposes of premiums. If asked to voluntarily contribute to public insurance, only unhealthy workers enroll. In some cases 80 to 90% of the workforce is non-trackable, making it impossible to impose premiums on them. This means that high levels of government subsidies are required to expand coverage to informal sector workers, whether it be through public insurance or tax-financed public services. Not every country is therefore in a position to cover all members of the population due to the high cost involved. In such economically-constrained situations, in some countries the governments opt to provide only limited coverage. Others however provide very generous services notwithstanding the limited funds available, Thailand and Malaysia being two examples. The key challenge for countries is therefore to decide whether to charge all members of the population a fixed rate and risk penalizing the poorest, or provide a smaller benefits package to cover all people.

In terms of the generosity of coverage and the expanding breadth of services that are covered, out-of-expenditure has not fallen as much as might be expected, and in some countries (notably Vietnam) out-of-pocket expenditure has actually increased over time. However, as Fig. 3 shows the health insurance coverage has had some degree of impact.

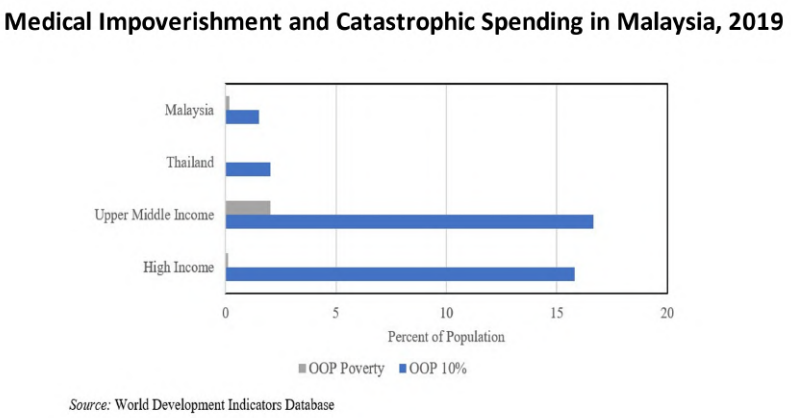
Figure 3: Change in out-of-pocket expenditure



Conversely, however, the amount of people experiencing catastrophic healthcare expenses (more than 10% of total income) has not declined, except in Thailand and Vietnam. This indicates that while coverage has increased, affordable access has not yet been guaranteed.

In the case of Malaysia, medical impoverishment and catastrophic spending levels are quite low, which is a remarkable achievement.

Figure 4: Comparison of catastrophic spending in Malaysia and other countries



Source: World Development Indicators Database

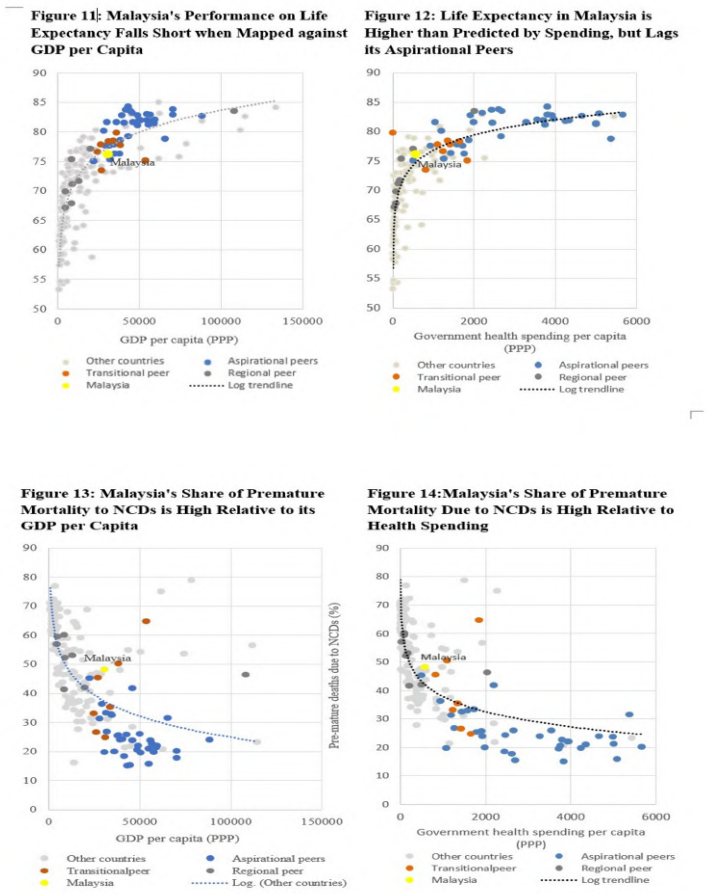
The proportion of population covered by health insurance systems has therefore improved, but remains incomplete. The proportion of people covered should not therefore be confused with universal health coverage (UHC) as these are two different concepts. Much of the health insurance funding has been focused on hospitals rather than outpatient services, one of the reasons for this being government funding constraints. While Japan and Australia each spend more than 10% of total GDP (2019) on health, LMICs such as China, India, Indonesia and Thailand spend considerably less. This is why LMICs are constrained in terms of the services they can offer.

Another issue that arises is inefficient use of resources. The high share of out-of-pocket spending is an illustration of fragmented funding. Out-of-pocket expenditure is essentially incurred by households, and it is not generally possible to negotiate with health service providers on an individual level. Due to costs involved in healthcare services people are not incentivized to visit hospitals or clinics for preventive care and screening. This is why in many LMICs people only present at hospitals or clinics with advanced stage disease. Hospitals and service providers are also disincentivized to provide preventive care because they can get more income from treatment of disease rather than preventive measures.

Another issue is that doctors and healthcare sector workers tend to receive their education from the government education system and then gain employment in the private sector, where wages are higher.

In Malaysia, roughly half of spending on health comes from the government, and 40% is accounted for by out-of-pocket expenses.

Figure 5: Life expectancy and premature mortality in Malaysia



One area where Malaysia is not doing as well as might be expected is in its treatment of non-communicable diseases (NCDs), with higher mortality than average. This points to opportunities for action in Malaysia in the future. Malaysia needs to invest more in primary care, especially with regard to NCD prevention and chronic disease management, and invest heavily in prevention. Malaysia also needs to get a handle on how to regulate its private health insurance sector and other issues relating to out-of-pocket spending.

(4) Considering the equity dimension of healthcare coverage in Asia and measures to improve affordable access

Some of the issues relating to affordable access may reflect the inability of some population subgroups to access health insurance benefits (e.g. due to a lack of awareness of eligibility). Another issue is the "missing middle" (often those who are close to poverty)

who do not voluntarily pay premiums. Malaysia covers everybody in its health coverage system, including the near-poor.

One of the reasons that out-of-pocket expenditure has not disappeared entirely may reflect a decision among the populace to seek care instead of going without care, due to increasing disposable incomes and initiatives or systems instigated by the government. It is therefore important to look at the use of services in each country and consider the degree to which spending on healthcare services is discretionary by users, who are enjoying increasing incomes in recent years.

In terms of what can be done to improve affordable access to healthcare services, a focus on prevention is very important. Another issue is the need to invest in coverage of primary care, for example early identification and management of chronic conditions, and incentivization of private providers for screening.

Another and more technical issue, is to promote effective use of payment mechanisms to promote referral linkages across healthcare providers, and cost containment. Another key challenge is to ease administrative processes for enrolment and also for awareness campaigns.

Malaysia is implementing a variety of initiatives to promote health and improve affordable access. These include tobacco taxes and a proposal to ban the sale of tobacco products to Malaysians born after 2007. The Malaysian government is also implementing an enhanced primary healthcare initiative to improve patient engagement and promote continuity of care and management of chronic conditions.

Another area where Malaysia is making efforts is to improve coordination among hospitals through the cluster hospitals program. It is also funding subsidized screening services for the poor population (for conditions such as diabetes and hypertension, etc.).

Discussion

Sonoda: One of the core messages of today's lecture is the importance of prevention when it comes to the effectiveness of healthcare systems and the various factors that help to achieve UHC. Professor. Mahal's lecture is based on his economic approach, but the various issues raised also relate to politics and political policies. The strength and the development of private sector healthcare in Malaysia suggests that there is a historical tendency towards small government, so what is the degree of political involvement in health in Malaysia and other countries?

Mahal: I deliberate skirted around political influences so that we could identify the core issues. Ultimately all politics is about self-interest and the various choices are very often a choice for one group at the expense of another group. In the case of Malaysia, the government has adopted a policy that focuses on private sector development in healthcare. Any effort to regulate the private sector results in strong pushback within the government of Malaysia. Malaysia is perhaps one of the most underregulated private healthcare systems in the world. There have been at least eight healthcare sector reform efforts in recent years and all have failed to be taken through to a successful conclusion due to resistance from the private sector. The case of India is similar, in that the private sector has developed broadly and rapidly to the detriment of the public sector in many states. In one of the Indian states a former doctor came to political power, and he launched a scheme in 2007 to provide generous coverage and in the next election he won by a landslide. This prompted other states to introduce similar schemes, but a major challenge is underfunding. A major reason for the Chinese Community Party's focus on health insurance is because severe disease can be economically destabilizing. The involvement of politics can therefore be facilitative, but it can also present obstacles.

Sonoda: There is a discrepancy between the scientific approach and the realities of societies and cultures in each country. In medicine and healthcare each patient is unique and it is very difficult to provide a one-size-fits-all approach. Malaysia is a country that has unique traits and it is important to combine a scientific approach with approaches that take into account socio-cultural aspects.

Q: There is no health insurance system in Myanmar, so it has been very interesting to hear about the various systems in Asia. With regard to the "missing middle" (near-poor), what is the situation in low-income countries?

Mahal: I have worked with colleagues from Myanmar and around 2012 when the previous regime was in power there was a township insurance plan that was introduced on a pilot basis in about 10 townships. In terms of the notion of the "missing middle," it has a very particular connotation in the insurance world – it refers not to the rich (who can afford care from anywhere), nor to the very poor (who evidently require assistance), but the rest of the

population, who cannot be identified as poor, but neither are they rich. The primary issue with this group is their lack of coverage, so that if they do become sick they are likely to fall into the poor sector. As healthcare costs are not predictable there is a high risk of catastrophic out-of-pocket expenditure in the case of severe disease. In Malaysia there is not so much of a problem of a missing middle, because the national health system does offer coverage to the general population.

Q: In the case of China companies are supposed to pay for healthcare insurance, so what is the case in Malaysia?

Mahal: I think you are talking about the Urban Employees Health Insurance Scheme, which is a heavily subsidized scheme by the government, and the situation is very different in rural areas in China, where people who work in the informal sector cannot be tracked. 91% of India's workers are in the informal sector, and in Indonesia it is around 75%.

Q: There seem to be many challenges between the government sector and the private sector. Are there any strategies to overcome out-of-pocket expenses?

Mahal: In the case of Korea there are high levels of out-of-pocket spending, but in this case it is mainly the rich population that is paying for care. In terms of out-of-pocket spending for poor people the reality is that they are much more sensitive to out-of-pocket spending, so such people who are living on the margins of poverty and who rely on physical labor should be provided with full coverage. There are some very interesting papers on this issue and long-term inter-generational poverty caused by out-of-pocket spending.

In the case of Malaysia, the Ministry of Health is not receiving sufficient funding from the Ministry of Finance and this is impacting prevention and screening programs. The government is reluctant to regulate the private sector in Malaysia because it has a vested interest in the system.

Kawahara: Thank you for a very profound talk today, and I hope that it will inform the roll out of the BEAUTY and Health Program.

Lecture No. 5

Understanding the psychological mindset of a cancer patient

Lee Kah Yee

Clinical Psychologist, National Cancer Society Malaysia (NCSM)

(1) Introduction to the lecture

Dr. Kawahara introduced the lecturer, Ms. Lee Kah Yee, noting that the lecture would be very useful for students who do not have a background in medical sciences, in order to order to understand the nature of the disease of cancer. Cancer is a very complex disease and has a strong psychological component. It is said that during the first two weeks after being diagnosed with cancer, a patient may not be able to make decisions.

A great deal of knowledge has been accumulated through Ms. Lee's work with patients, which is available online and via her SNS sites. The lecture will also explore how Ms. Lee is trying to expand understanding in society about cancer. This field is also key to understanding better the BEAUTY and Health Project.

Ms. Lee noted that she would be talking about the mental aspects of cancer and how mental health can affect cancer and the well-being of patients.

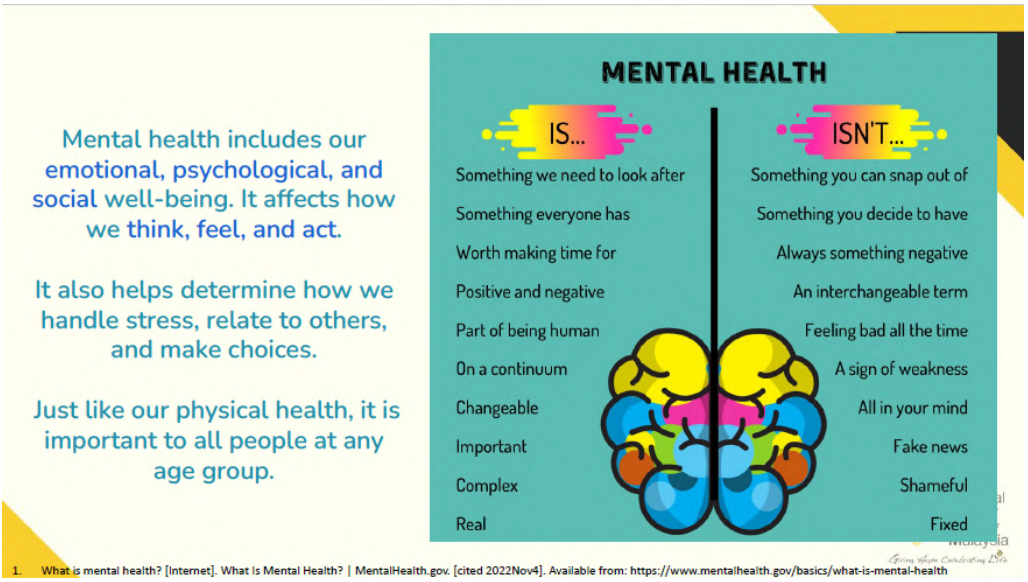
(2) Cancer and mental health

In Malaysia many people tend to perceive mental health as a shortcoming, a personality weakness or character flaw. Some people also tend to think that people can never recover from mental health issues, or that it only affects certain people. These misconceptions have been perpetuated over the years.

Mental health includes our emotional, psychological, and social well-being. It also helps determine how we handle stress, relate to others, and make choices.

Just like physical health, mental health is important to all people in all age groups.

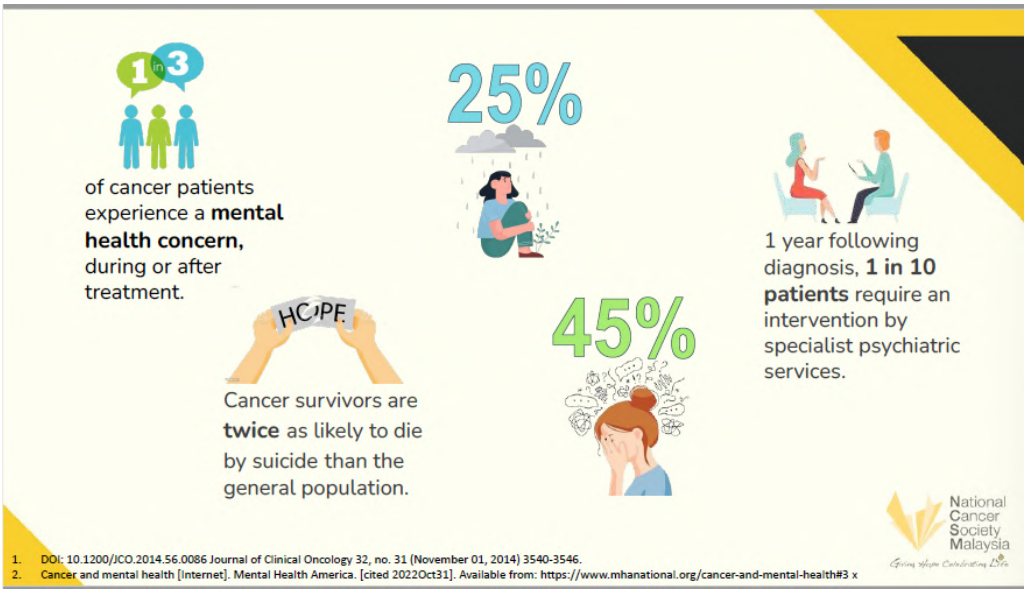
Figure 1: Overview of mental health definition



As shown in the figure above, mental health is complex and has a variety of causes.

A cancer diagnosis can have a significant negative impact on mental health, as shown in the figure below.

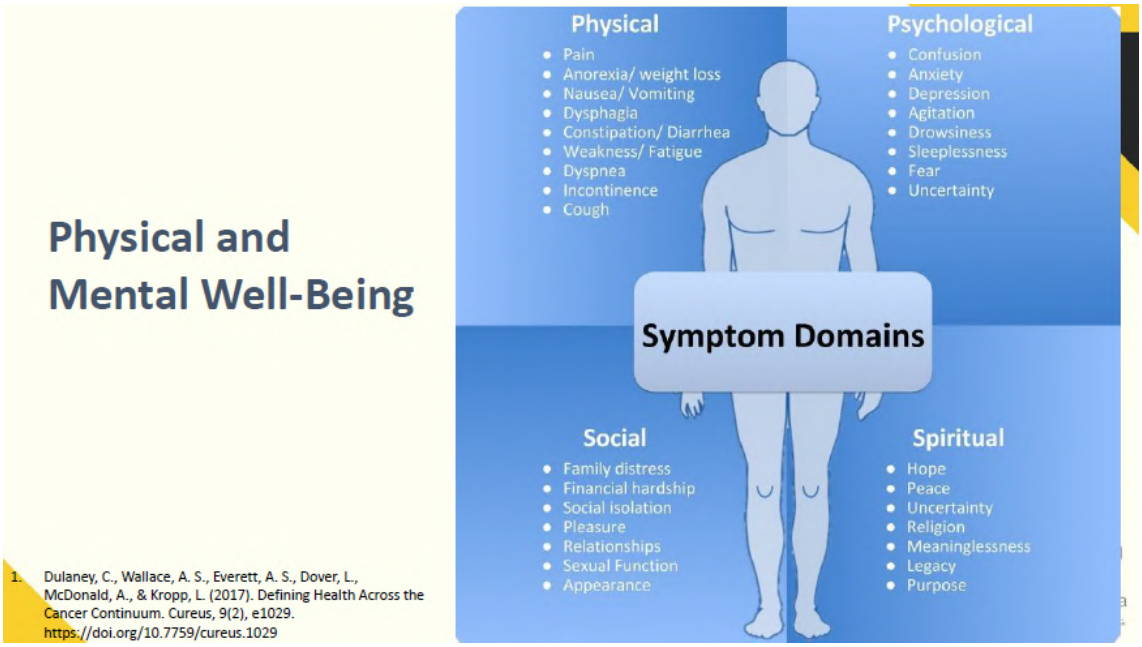
Figure 2: Effect of a cancer diagnosis on a patient



(3) Emotions and cancer

Cancer patients went through all this stage along in their cancer journey. From screening, diagnosis, treatment, survivorship or end of life care, it all represent a heavy physical, mental and social burden. Physical and mental well-being can be subdivided into a variety of symptoms as shown in the figure below.

Figure 3: Symptom domains relating to cancer



A diagnosis of cancer can make people feel overwhelmed, wondering if they are going to live and also being affected by disruptions to their daily lives. People can also feel overwhelmed when they hear medical terms that are difficult to understand. They may feel helpless and lonely.

A cancer diagnosis can also cause anger, coming from feelings that are hard to show and based around the question, “Why me?”

Fear and worry are also manifestations of a cancer diagnosis, with people worrying about pain from cancer and its treatment, or how they will take care of their family and how they will pay their bills.

People also feel vulnerable and helpless, questioning themselves and asking many “what if” questions. This may lead to feelings of guilt, with people worrying about becoming a burden or envying others’ good health, or regretting their lifestyle choices.

Once people accept that they have cancer, they often feel a sense of hope. It doesn’t mean they have moved past the grief or loss. It does, however, mean that they have accepted it and have come to understand what it means in their life now.

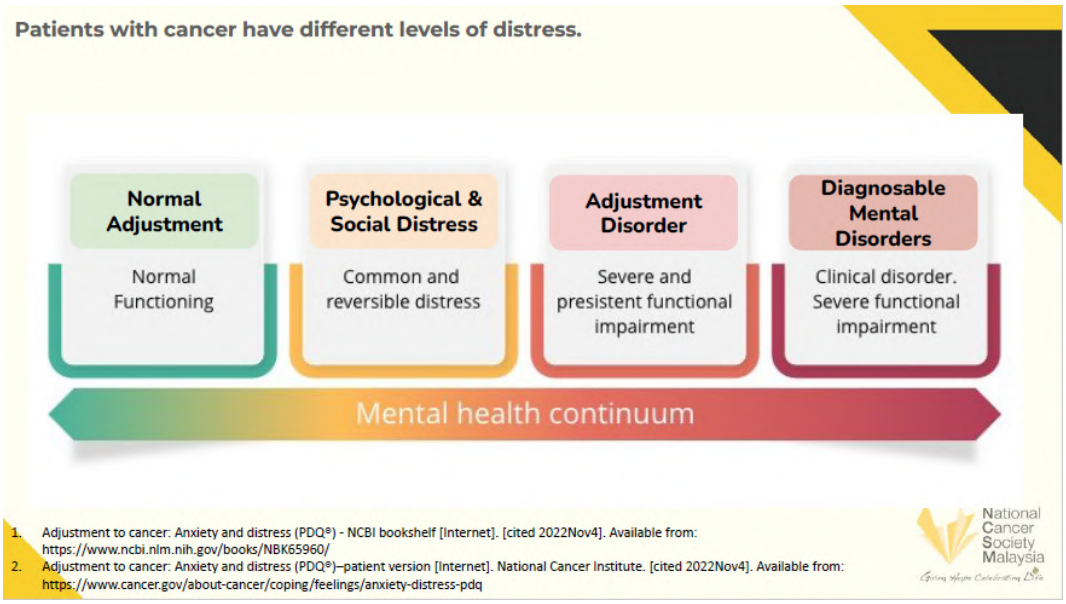
It is important to note that not everyone will go through all of these emotions stage by stagey, Also they might not happen in order. Some people have described a “roller coaster effect,” with lots of wild swings between these emotions.

(4) Adjustment to cancer

Studies show that the prevalence of mental disorders in cancer diagnosis shows that cancer patients do not meet diagnostic criteria for any specific mental disorder. However, many people may experience a variety of difficult emotional responses. Distress can affect the quality of life of patients with cancer and their families.

Distress is an emotional, mental, social or spiritual suffering. Distress can present with a range of feelings, from sadness to a loss of control and depression, anxiety, panic and isolation. It may also cause physical problems, such as nausea, having more pain than usual, or sleeplessness. Patients with cancer have different levels of distress, as shown in the figure below.

Figure 4: Levels of distress in cancer patients

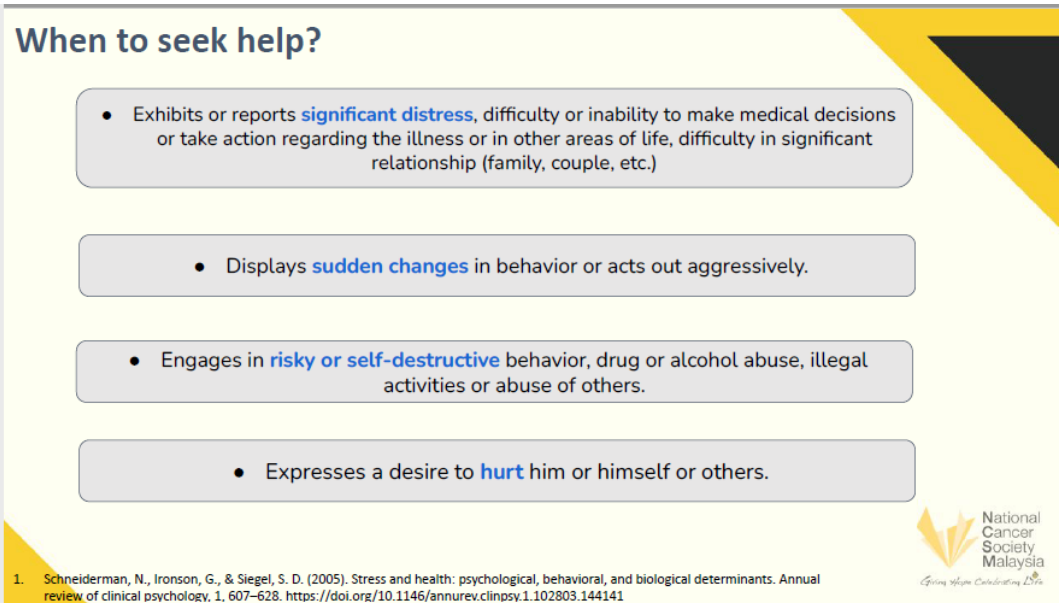


Levels of distress range from normal adjustment through to diagnosable mental disorders. Normal adjustment means that the patient learns to cope well with emotional distress and solve problems related to cancer. In the psychological and social distress stage patients have some trouble making changes in their life and may experience feelings of depression, panic or spiritual crisis. In the adjustment disorder stage, patients experience a great deal of trouble making changes in their lives. Symptoms such as depression, anxiety or other emotional, social or behavioral problems may occur. Diagnosable mental disorders stage includes clinical disorders that entail severe functional impairments that affect a person's ability to lead a normal life.

There are various signs of mental illness in cancer patients, including feeling anxious, feeling depressed, emotional outbursts, sleep problems, weight or appetite changes, becoming quiet or withdrawn, substance abuse, feeling guilty, or changes in behavior and feelings.

In terms of when cancer patients need to seek help, signs could include the following, as detailed in the figure below.

Figure 5: Signs that a cancer patient may need to seek help.



In terms of where to seek help, a patient can reach out to support groups, or considering counseling or psychotherapy, or consult a doctor.

(5) Psychological intervention

In psychological sessions sometimes Ms. Lee uses one-on-one therapy and counseling. In these sessions it is possible for patients to focus on what they are most bothered about and learn ways to cope with their cancer and changes in their life. Sessions also help patients to deal with symptoms and figure out how to handle changes, such as end of treatment and what to do if cancer recurs.

Other options are couple or family therapy, and also group therapy. Family therapy helps family members to improve how they express their feelings and help resolve conflicts and help them come up with ideas about how to work together better.

Compassionate emotion-focused therapy (EFT) provides a comforting presence and

practical support. It creates a safe and serene atmosphere for patients to express their emotions and enable them feel at ease and allay fears about the disease. EFT also attempts to expose patients to positive aspects of life, deviating their mind from agonizing trauma and suffering. As a psychologist it is important to be a proactive listener and let patients talk first.

Another form of therapy is cognitive behavioral therapy (CBT), which helps patients to learn whether their coping methods are healthy and helpful. It is also to help cancer patients to identify any negative automatic thoughts they are having and understand how it affect their behaviors, emotions, and physical sensations.

Sessions also include meditation and mindfulness exercises, as well as self and gratitude reflection. The benefits of meditation and mindfulness exercises include, feeling grounded and focused on the present moment, avoiding feelings of worry about future events, reducing pain and enhancing the body's immune systems, reducing feelings of depression, anxiety, anger and confusion, providing a sense of calm, peace and balance, increasing energy and strength, and helping control thoughts.

Relaxation techniques are also important, including box breathing, deep breathing and progressive muscle relaxation. The benefits of relaxation techniques include: lowering overall tension and stress levels, helping patients relax when they feel anxious, preventing and alleviating chemotherapy-induced nausea, improving sleep quality, decreasing blood pressure, and helping calm patients' minds.

Another important aspect during cancer treatment is self-care, including exercise, keeping a journal, eating nourishing foods, staying connected with family and friends,, scheduling "me" time, and knowing that it's normal to have bad days.

Discussion

Sonoda: Today's talk was relatively broad and in the university context there are also situations in which you may come across people who are experiencing mental health issues. It can be difficult for a third person to approach a person and suggest that they seek help or therapy, particularly if the person in question doesn't recognize that they have a problem. What sort of techniques would you recommend people to use when they are trying to encourage cancer patients, they know to seek help?

Lee: There are a lot of cancer patients who are in denial about their disease. It is first

necessary to listen actively to what the patient has to say. Family members may tend to give advice rather than listen, but the first priority should be to listen to the patient's own feelings and experiences. It is important to listen what the patient is saying and try not to give suggestions immediately, but give them time to express themselves.

Sonoda: It seems that the people who want to recommend a patient to seek medical help will need to have a great deal of patience, particularly if they should not try to provide suggestions immediately.

Lee: When to seek help, and when to encourage patients to seek help can be difficult to determine, but as was shown in the presentation (Figure 5 above) there are situations in which it is important to recognize the necessity of seeking help. In situations in which the patient does not want to seek help, the first point of contact can be the patient's family. By providing information and suggestions to the family members can be a useful indirect way of encouraging the patient to see a doctor.

It is also important to remember that there is nothing that can be done if the patient is adamant that they do not want treatment.

Sonoda: What would happen if the patient's family approaches you to help the patient and advise them to seek help.

Lee: It is important to establish a rapport with a patient before making any suggestions.

Q: You mentioned that cancer patients may not wish to seek help for mental distress, but may be willing to visit hospital for physical symptoms. At what point do patients tend to become more open to receiving help for mental health issues? Is there any connection between the cancer staging (T1 to T4) and a patient's mental health?

Lee: Through my work at NCSM, most patients are experiencing psychological and social distress on the mental health continuum. Another interesting finding through my work is that most people experiencing severe mental disorders tend to be family members, rather than the patient themselves. In terms of a correlation between cancer staging and mental health, conversely more patients with Stage 1 and 2 cancers tend to have mental

disorders, whereas those with T3 and T4 cancers tend to be more accepting of their situation.

Q: Is counseling for mental health covered by the national health service, or is it self-pay?

Lee: Mental health professionals' fees in Malaysia are starting from around 250 ringgit per session but depends on the particular organization. CSM offers free sessions to patients, which helps to alleviate the burden of cancer on patients and their families. Patients are referred to NCSM via their primary medical provider.

Q: Given that Malaysia is a multi-cultural, multi-ethnic country, I would like to ask about if you have any information about how different ethnicities react to a cancer diagnosis and whether mental health issues are more frequently observed in certain ethnic groups.

Lee: The Malay population is less proactive in seeking help and lower-income Chinese ethnic groups are also less likely to seek assistance, instead going to receive Chinese traditional medicine. NCSM has found that most of the referrals and questions about mental health are from higher income Chinese ethnic groups. Awareness of mental health is tends to be low across the board among the Indian community, regardless of income.

Sonoda: What are the benefits of cross-disciplinary and cross-border collaborations, such as those between Malaysia and Japan?

Lee: I do believe that the international collaborations are important for spreading awareness about mental health literacy, not just for cancer, but for mental health overall. In such collaborations it may also be useful to talk about differences between the situations in respective countries and make collaborations more fruitful.

Kawahara: Perhaps the wisdom shared in this lecture will link through to the BEAUTY and Health Project, which is also linked to mental health and general well-being.

Lecture No. 6

Understanding the perceptions of target audience to health education materials in Malaysia

Mandy Thoo

Manager, Health Education, Literacy, Promotion and Policy, National Cancer Society Malaysia (NCSM)

(1) Introduction to the lecture

Dr. Kawahara noted that for the BEAUTY and Health Project in Malaysia the important issue is what kind of learning and information about cancer can change people's behavior. It is important to understand how emotions and their impact can be effective in order to implement the project. It is necessary to look deeply into people's minds. She noted that today's lecturer would by Mandy Thoo, who is the current Head of the Health Education, Literacy, Promotion, and Policy (HELPP) department at National Cancer Society Malaysia (NCSM).

Dr. Kawahara noted that in the Q&A session of the lecture, Jane Aiko Yamano, President of Yamano Gakuen would also be taking part in discussions.

(2) What is health communication and what is health education?

The Society for Health Communication defines health communication as the science and art of using communication to advance the health and well-being of people and populations. If you have given some form of health advice or message to someone in your life, you have done some form of health communication. Education is the larger umbrella that is designed to improve health literacy. So you have communication and you use communication to work on health education, in order to improve health literacy.

Health literacy is not just a person knowing what a health-related term means, but that they also can use the knowledge. So literacy does not include only the communication of information, but also encourages or helps people build skills as well as confidence to use what they know about health.

In terms of why health communication is important, participating students suggested that it is an important method of imparting knowledge to people. Another reason health communication is important is that in normal daily life there are few opportunities to know about health, and therefore health communication in the community can play an

encouraging and enabling role in raising awareness. Health communication also helps to bridge knowledge gaps and reduce reliance on healthcare professionals.

Two health communication videos were shown, one concerning ways of reducing the risk of cancer, and another more commercially-oriented video promoting vaping instead of smoking.

Next, printed materials used in Malaysian awareness campaigns for cervical cancer and preventing smoking were shared.

Students noted how these videos and printed materials are very different in the approach they take, one being more clinical in nature and one being designed like a TV commercial.

One issue that is faced is that the clinically-oriented videos/materials sometimes do not get a good reaction from test audiences.

It can be quite difficult to develop materials without a clear picture of who the audience will be. Due to budget and time constraints very often the materials developed are based on a "one-size-fits-all" approach.

Despite everyone having different backgrounds, there are some universal aspects of our lives that remain unchanging, and in the case of the BEAUTY and Health Program, the common factor is the motivating factor of beauty.

All health communicators are competing for resources that are finite and it is important to find ways of grasping people's attention and gaining their engagement. Attention spans are getting shorter and shorter in today's SNS, Facebook, YouTube, Instagram and TikTok-oriented society. It is therefore important to remember when communicating information about health that the materials being used are competing with many other materials/ videos, etc., that people may be more inclined to watch.

(3) Overview of the BEAUTY and Health Project

The BEAUTY Phase 1a study is titled "Do I like what I see?" and the aim is for a cancer health education intervention program to: 1) explore and understand the content required to develop a series of health education materials, 2) explore and understand the cultural requirements of health education materials, 3) develop health education materials, and 4) validate the materials.

Health communication has benefits for both patients and healthcare professionals. For patients, there are the benefits of improved understanding of condition, improved understanding of methods and means to manage medical condition, improved self-advocacy, and increased motivation to comply with treatment. There are still strong traditional beliefs in Malaysia that may distract patients from seeking care.

In terms of the benefits of health communication to healthcare professionals, these are: increase compliance of patient to treatment plan, improved patient outcomes, improved cooperation as patients feel they are more involved, improved informed consent, and reduced use of resources and increased patient satisfaction.

Another key point to consider is who is providing/managing care in the community, and this can include primary healthcare providers, community health workers, friends and family, and other members in the community. Students noted that very often in rural communities it is families and friends that are key care providers/managers. In contrast to the time spent with doctors, patients spend the vast majority of their time at home and in the community, which means that it is friends, family and local community members who have the largest role to play.

A key concern is what to do when there is a mismatch between what patients need to know and what they actually know with regard to cancer. In the last five or six years there was a paper on public health that listed six reasons why public health doesn't work sometimes. The first reason is because it is assumed that all human beings are rational, but this is not necessarily the case.

For example, in terms of the example of baby-led weaning, one of the successes in expanding this practice was not the advice of healthcare professionals, but rather the positive experience of mothers.

There are many health campaigns through multiple channels, so if all human beings are assumed to be rational, how is it that non-communicable diseases are still rising? If campaigns truly work there would be a much narrower gap of knowledge, attitude and practice between health and society. It is important for health communicators to pay close attention to their audience. Thought needs to be given to materials targeted to a particular audience, and it is equally important to test materials prior to their rollout to assess uptake and understanding among the general populace/patients. After receiving feedback after a test-rollout it is then important to make the necessary adjustments.

In terms of the BEAUTY and Health Project, from literature reviews it is known that

patients want information. Patients prefer printed materials for refresh and recall purposes, and also prefer to have material first explained by health professionals. However, some patients who possess a certain level of health literacy can find current materials too simple in their approach to the extent that they appear condescending. These kinds of people would prefer to receive materials through multiple media channels. It is necessary to respond to these various learning needs.

A total of six theories have been referenced to build a theoretical framework for the BEAUTY and Health Project. These are Ausubel's Assimilation Theory, Cognitive Load Theory, Atkinson and Shiffrin's Information Processing Theory, Pintrich's Metacognitive Knowledge Theory, Vygotsky's Zone of Proximal Development Theory, and Bruner, World and Ross' Theories on the Concept of Scaffolding.

The above theories are then matched with theorized educational problems, including difficulty in assimilating knowledge, large intrinsic cognitive load, knowledge decay, lack of metacognitive knowledge, learning tasks outside zone of proximal development, and lack of scaffolding (i.e. guidance/materials).

As efforts are made to understand the stage of understanding among people with regard to cancer and factors influencing individuals' learning it is important to consider whether current cancer information materials are sufficient and whether the "one-size-fits-all" approach is appropriate.

To do this effectively, under the BEAUTY and Health Project, focus group discussions and cross-sectional surveys are being implemented.

In Phase 1 there are four arcs that require attention: 1) awareness and use of current cancer health education materials, 2) cancer information needs and how they are fulfilled, 3) assessment of current cancer health education materials, and 4) preferences for cancer health education materials.

The questions used in the focus group discussions concerning awareness of the types of health education materials include the following: Have you seen materials? What do you recall? How frequently do you see the materials?

With regard to cancer information needs, sample questions are: What information have you sought in the past few years? How did you seek the information? From where did you get the information? What was the quality of the information?

With regard to assessment of current materials, sample questions are: Was there anything you especially liked/disliked? Was there anything confusing? How useful was it?

With regard to preferences for cancer health education materials, sample questions are: What types of format do you prefer? What is your preferred channel? What is your preferred type of content? What is your preferred type of take home messages?

In the cross-sectional survey, people were asked to answer a variety of questions with “disagree” or “agree” responses. At the end of the survey the scores are totaled to calculate an understandability score. These surveys are available in both printed and online formats.

In terms of outreach to people, communication campaigns and advertising campaigns are very different. Communication campaigns have a persuasive focus (seeking to encourage behavioral change), whereas advertising campaigns have a perception focus (on a specific product). Whereas communication campaigns aim to challenge specific desires or wants, advertising campaigns aim to satisfy desire and wants. A communication campaign may involve personal cost or discomfort, whereas for an advertising campaign, the main cost is choosing among brands. Communication campaigns can be sensitive, obtrusive and emotional, whereas advertising may not involve emotional or affective attachment.

In terms of communication objectives, communication campaigns tend to be unclear, in contrast to which advertising campaigns are very clear.

A key sticking point for communication campaigns is that information may be perceived to be unreliable. This is because groups may think that the information does not concern them, or that they are already compliant with the required actions / lifestyle changes. Advertising campaigns, on the other hand, while accessible and positively viewed, may not necessarily have a massive effect in influencing behavior.

It is imperative to pay attention to how health education and communication are being perceived by their audience. Communication is both a science and an art and a dual perspective is important. On the part of science, it is important to analyze, design, manage, and evaluate communication interventions, and for art side the key points are creativity, judgment, experience, intuition and insights when communicating with others.

Discussion

Jane Aiko Yamano: As you mentioned, communication is both a science and an art. At the Yamano Beauty College and Yamano College of Aesthetics we offer a wide range of beauty and welfare courses. Beauty is something that reaches out to people regardless of gender, disability, or outlook. It is hoped that the BEAUTY and Health Project will help to make people feel more confident, because when people are confident, they are more likely to go out and do more. Communication is taken differently depending on country and age group. In Japan, cancer is something that people feel they should hide, whereas in the U.S. there are many communication groups where patients can come together and talk about their experiences of cancer together.

It is therefore very important to understand your audience and identify the key message that you are trying to get across.

Some doctors have a poor bedside manner, and it is hoped that reaching out to people through beauty salons and barbershops will make it easier to talk about challenging subjects. People also see their barber/beautician on a much more regular basis than their doctor. It is positive for society to be able to look good and feel good and the communication that takes place at salons can be very beneficial for cancer care.

To have “total beauty” there are five elements of “bido” (the “way of beauty”): hair (cutting, color, treatment, etc.), face (smiling), makeup (boosting self-image and shaping face), fashion (including national dress across all Asian countries), and mental and physical health.

Our courses at all of our Yamano schools attempt to combine beauty with welfare, because beauty, looking good and feeling good has a tremendously positive impact on well-being. In terms of mental and physical health it is important to feel able to talk about your condition. It is also important to be able to talk about cancer because of the tremendous importance of prevention and early detection.

Although a person may not be 100% healthy physically, if they think positively and go out and get their hair done, etc., it will help them to feel better. At the end of the day, it is important to smile and be happy.

It is to be hoped that the beauty industry can help to make a positive impact through this project and also gain insights that will be useful for the beauty industry.

Sonoda: It is very significant to combine mental and physical health factors with beauty. When I was walking at the international division of the university we had a collaboration with the University of Peking, and we created a program to learn cultural nuances through this collaboration. Several Japanese companies and industries were approached to inquire about the efforts that were being made so that services and goods would be well-received by Chinese consumers. This project also included Japanese beauty companies and they emphasized the importance of communication and person-to-person interactions.

Thoo: Beauty is universal, as is health. In this project there is a great combination of both science and art that are well-positioned to be drivers for changing people's behavior. Beauty is hard to resist and has the real ability to give people confidence.

Q: With regard to the survey that is planned for the project, how will the impact of the project's message be evaluated?

Thoo: Whereas in an ad campaign you would be able to track effectiveness very quickly, in a health communication campaign the response is not so quick. However, there is a "theory of half," whereby half of the audience will remember the message, and then half will be responsive, and half again will take action.

Q: Will BEAUTY Project beauticians in beauty salons need to have specialist medical knowledge?

Yamano: I don't think that specialist knowledge would be required, but they should be prepared to give advice and encourage customers to either see a doctor or go for cancer screening.

Q: What are the subjects that it would be best to raise in barbershops and beauty salons? What kind of information would make people more responsive or positive about the message? It is important to ensure that customers remain relaxed and are not put off by the message.

Thoo: A communications campaign can be a bit confused about what it is trying to

achieve. In the beauty salons, therefore, what do we expect the audience to do? Do we want them to remember everything that the beauty salon staff tell them, or provide sufficient information that they recall the conversation and then refer to the printed materials to recall the content? It is important in this case to test the material that is planned to be distributed. If customers are visiting a beauty salon it can be assumed that they have an interest in beauty or maintaining a certain level of presentation. It is therefore important to train beauty salon staff to be sensitive to their customers and adjust their responses accordingly.

Q: There is a tremendous volume of information on social media these days, but I think that we need to produce much more health-related materials for distribution through social media channels, because currently there are very few materials circulating on social media about health. From a consumer perspective, where can you find more information about health communication materials?

Also, with regard to interactions in beauty salons it is critically important to create connections between the staff and their customers.

Thoo: In the case of NCSM there are materials available through our official channels. However, there are vast quantities of health-related materials out there and the fact that they are not reaching you speaks volumes about their reach and efficacy. It also demonstrates people's interests and what they are searching for.

Health communication campaigns ultimately only result in the changing of behavior of a small number of people. It is out of a desire to improve the proportion of people whose behavior is changed that these beauty salon interventions are being planned.

Yamano: I think that visiting salons is a matter of gaining trust and improving communication that is a very important way of helping society. Education is so important because it is the unknown that people fear. When you gain the trust of a customer it will hopefully make it possible to help that customer be healthy and encourage them to maintain their health. I hope to hear more about the project in the future.

Lecture No. 7

40th Anniversary of the Look East Policy

Katsuhiko Takahashi

Ambassador of Japan to Malaysia

(1) Introduction

Although I am not an expert on cancer, I agreed to take part in this seminar because I am in a position to speak to a certain degree about Japan-Malaysia relations and the need for continued cooperation on various issues. Also, although the greater part of my diplomatic career has related to the Middle East, I have also had an opportunity to work on issues related to the Surviving Cancer in Asia seminar series, including Universal Health Coverage (UHC) and human security. Particularly with human security, I was deeply involved in negotiations that led to the adoption of the UN General Assembly Resolution on Human Security in September 2012, and I worked closely with the late Mrs. Sadako Ogata on this issue.

(2) Look East Policy and its achievements over the past 40 years

The Look East Policy (LEP) is a Malaysian policy with a long history. It was 1982 in Kuala Lumpur at the Joint Annual Conference of Business Communities of Japan and Malaysia, where Prime Minister Mahathir stated, “I have been exhorting Malaysians to emulate the Japanese, particularly in work ethic and ethical values, and we have come to realize that the basis of your rapid development is your sense of commitment and your continued willingness to work.” The Prime Minister’s Office of Malaysia then described the LEP as follows: “This policy means that the government of Malaysia will make a study of the best examples and role models from Japan and Korea by adapting it to the conditions in Malaysia.”

People tend to believe that the LEP relates to Japan-Malaysia relations, but it is important to note that Korea was also included in its scope from the beginning.

What Dr. Mahathir envisioned originally seems to be bigger than the policy line of the government, but Japan has been helping Malaysia to implement the LEP positively since then, because Malaysia was the only country at that time to create a Japan-specific policy. So, what has been achieved so far?

As a result of the LEP, more than 26,000 Malaysians have received training or education. From the beginning Japan helped to prepare curricula for Malaysian students before their study in Japan, including preparatory courses in Japanese language, mathematics and

physics. Japan also tried to provide vocational training opportunities in Malaysia, including the opening of vocational training institutes in Malaysia, such as Malaysia-Japan International Institute of Technology (MJIIT).

The dispatch of students and trainees created a positive cycle of HR development and investment. Now more than 1,600 Japanese companies are operating in Malaysia, which is a larger number than in other ASEAN countries. This fact itself is regarded as a remarkable achievement. Evaluation of the LEP needs to be done by the Malaysian side, but Japan hopes that it has helped Malaysia to develop its economy to its current level. Malaysia still needs to learn a lot from the outside world and HR development is needed to move from low-skilled manual labor to high-end skilled industries. For example, 30 years ago Japan helped Malaysia to set up their own automobile industry, with the help of Daihatsu. Thirty years have passed, but certain components still need to be imported from Japan, but cooperation continues.

Thanks to the LEP Japan is in a privileged position in Malaysia, therefore the best way is for the two countries to continue to use this existing channel to provide mutual benefit. Also, the need for working ethics and ethical values that Dr. Mahathir tried to learn from Japan still exists and Japan is ready to extend a helping hand to Malaysia if needed.

On the other hand, the situation has changed domestically and internationally, and we should not take for granted an existing friendly relationship between the two countries based on the LEP. Rather, we should continue to enhance the LEP and take it to the next stage. This is precisely the discussions that have been taking place between the governments of Japan and Malaysia in recent years.

As a result of a series of high-level meetings, Japan and Malaysia have agreed to take the LEP further, and under new Prime Minister Anwar it is hoped the policy will continue.

(3) Look East and beyond – the future for LEP

There are two modifications that are needed for the LEP, the first is modifying the scope and the second is modifying the relationship, and both modifications have two approaches.

First, with regard to modifying the scope of the LEP, the first approach is to expand the scope of manufacturing. LEP focused on manufacturing from the outset, and we can continue this focus, but with some modifications due to the advancement of technology in the past 40 years. This kind of modification has been discussed for the last 10 years, since the 30-year anniversary, and Malaysia has elaborated the kind of cooperation it is seeking. This includes areas such as digital, cybersecurity, 5G, aviation industry and renewable energy. Japan and Malaysia have also agreed to discuss creating resilient supply chains in

the wake of COVID-19. This kind of cooperation will continue to be the major pillar for the LEP.

Another modification of the scope of the LEP is to expand the scope beyond manufacturing. A new approach needs the involvement of other ministries in Malaysia. One example for further cooperation is disaster risk reduction (DRR). Although Malaysia is not susceptible to major disasters like Japan, awareness of risk, due to climate change and other factors is increasing in Malaysia. Discussions are ongoing between Japan and Malaysia on how to mitigate disasters, including more accurate weather forecasting, etc. This is one area where there is potential for new cooperation under the LEP.

Another example where the LEP could be utilized is preparation for an aging society. Aging is a relatively new issue for Malaysia, but by 2044 14% of Malaysia's population will be over 65. Japan's population reached that level in 1994, meaning that there is an approximately 50-year time lag between the two countries. Therefore, in order for Malaysia to prepare for a future aging society, it would be useful to draw lessons from Japan. Aging is a multifaceted issue and includes lots of elements, including social security systems, healthcare, care home management, and discussion on how to provide dignity in old age. Japan has experienced challenges much earlier than other countries and new measures continue to be introduced as society ages. Japan is therefore in a position to show Malaysia the successes and failures of aging-related policies. Malaysia also hopes to cooperate with Japan on the issue of aging. The Sultan of Selangor is keen to learn from Japan on the issue of aging and it is one important area for collaboration.

Another potential area for cooperation under an expanded LEP would be healthcare, including cancer treatment. UHC has been promoted in the context of the Japan-ASEAN framework and Japan concluded the ASEAN-Japan UHC Initiative with ASEAN countries in 2017. In line with this initiative, Japan will develop HR and share knowledge for strengthening health systems to realize UHC in ASEAN countries.

For Malaysia specifically, healthcare could be one new and promising area for the LEP. Japan has already contributed to preparing medical infrastructure in Malaysia, and Japanese companies have started to invest in Malaysian medical services. During the pandemic Japan also offered assistance to Malaysia, and there is a hope that more can be done in the area of healthcare in the future. Japan and Malaysia already have several initiatives ongoing in the medical field. The most outstanding initiative among these is Japan-Malaysia collaboration on clinical research, especially for cancer treatment. On the Malaysian side, Clinical Research Malaysia (CRM) was established by the Ministry of Health in 2012 and is playing a critical role.

Last month in Kuala Lumpur CRM and Japan's National Center for Global Health and Medicine exchanged an MOU to collaborate in three areas: 1) Building clinical research networks in the Asian region and worldwide, 2) supporting clinical research conduct and activities, and 3) strengthening clinical research capacity in the Asian region.

Also, CRM and the National Cancer Center of Japan exchanged an MOU on the Atlas Project in 2020, and last month engaged in an in-person meeting. The Atlas Project is the Asian Clinical Trial Network for Cancers, established by the National Cancer Center of Japan, and by exchanging an MOU Malaysia will benefit from early phase oncology drug development, cancer genomic advancement, and drug access and development. This MOU spells out collaboration in the area of cancer research that includes infrastructure development, training opportunities in clinical research, participation in rare cancer clinical trials, networking opportunities, as well as visits and attachments by research experts in both countries.

This collaboration in clinical research will not only benefit Malaysia, but also Japan. This is a new type of LEP and it should be promoted in line with other modifications to the policy. These types of agreements that benefit both sides can also be new elements for the LEP.

(3) Modifying the relationship under the LEP

It is with a view to benefiting both sides that the relationship under the LEP should be modified. The traditional LEP used to pay attention to dispatching Malaysian nationals to Japan to learn predominantly about manufacturing technology. In that sense the traditional LEP was one-way from Japan to Malaysia, in a donor-recipient relationship.

However, it is now important to assess the LEP in a new light. Just before the pandemic there were 400,000 Japanese tourists visiting Malaysia annually, while the number of Malaysians visiting Japan was 500,000. Also the number of students studying in each other's country was more-or-less balanced, with 3,000 students each. This indicates how balanced the relationship has now become.

As more Japanese visit Malaysia than before, now is a good time to learn from Malaysia. Diversity and tolerance is a value that Malaysia is proud of and Japan would do well to learn from Malaysia in this respect.

Another modification of the relationship is to enhance partnership. As Malaysia is situated between the Pacific Ocean and Indian Ocean it has great potential to be a regional hub in various fields, among others education and HR development. There is already the Malaysia-Japan International Institute of Technology (MJIIT) in Malaysia and work is

underway to establish a branch of Tsukuba University in Malaysia. These could become two hubs to promote Japanese-style education in Malaysia and could contribute to the future of Malaysia and the wider Southeast Asian region.

Clinical trials could also be a new partnership area for Malaysia and Japan and Malaysia could become a clinical trial area in Southeast Asia.

Discussions are continuing between the two countries on how to make LEP mutually beneficial.

(4) LEP, the new international situation, and human security

The Japan-Malaysia relationship is based on people-to-people relations through the LEP, which is quite unique. The LEP has made the relationship extremely resilient. A question now is how to best use this resilient relationship, particularly given the values that the two countries share. This is one reason whey Japan is promoting the concept of a free and open Indo-Pacific, because core values include the rule of law, free trade and safety of navigation.

Malaysia tries its best not to be involved in international conflict and avoid even making comments on difficult security-related issues. This approach is similar to Japan's approach in the 1980s, but after the Cold War ended Japan changed its approach to a more proactive stance. This is when Japan started to discuss human security, as a concept that contrasts to state security.

Human security is a notion that Malaysia can understand and demonstrate support for. By accumulating happiness and resilience through human security it is possible to create stronger societies and nations.

That is not to say that human security should be an element of the LEP, but human security represents a common approach of Japan and Malaysia, and human security can be the common approach by which Japan and Malaysia work together.

The LEP is all about uniting, connecting and collaborating, and by enhancing the LEP the common values shared by the two countries can be exported to other parts of the world and contribute to overturn anti-globalization sentiment as well as inclination towards division and disconnection. As ambassador to Malaysia I will continue to do my best to enhance the Japan-Malaysia relationship based on the foundation of the LEP.

This is the 40th anniversary year of the LEP, and it also represents a new beginning for the LEP. It is hoped that the policy can be further elaborated for the years ahead and the health sector is one very promising area in which the LEP can focus in the future.

Discussion

Q: Malaysia is starting to become an aging society, so in your view, what is the first thing that you think Malaysia should do to prepare for the onset of an aging society?

Takahashi: A sense of urgency is currently lacking and there is a need to look at the pension system of Malaysia in the future. There are a lot of challenges ahead and government funding is very much needed for social security, pensions and healthcare. The tax system is also another area that will require attention in the future in order to prepare for the coming of an aging society. A long-term perspective is critically important to prepare and it is to be hoped that the new government will concentrate on this issue going forward.

Q: I have a question about the LEP and what are the different things that Malaysia can learn from Japan and Korea, respectively?

Takahashi: In the case of Korea, Malaysia paid real attention to the pace of industrialization. Malaysia's intention was to learn from both countries, which have different backgrounds. The economic size of Japan and Korea was very different in the 1980s and the number of students dispatched to Korea from Malaysia was smaller. However, Korea now has some advantages in cultural and business aspects, and Malaysia is seeking to learn about different things from the two countries.

Sonoda: I understand the importance of the concept of human security, and I would like to hear your evaluation of the importance of cancer prevention under the huge umbrella of human security.

Takahashi: Human security is a very complicated notion and looks different from various perspectives. Therefore, if you look at the UN resolution on human security, there are maybe 12 paragraphs in total, half of which are dedicated to defining what is human security, and half of which are dedicated to what is not human security. Cancer treatment is one element of human security because health is one of the critical areas, together with poverty eradication and education. If you can prepare basic infrastructure for awareness and preparedness it can create a sense of security among the people.

Lecture No.8

Disparities in the Malaysian Cancer Care Landscape

Dr Saunthari Somasundaram

President of the National Cancer Society of Malaysia

(1) Healthcare system in Malaysia

Similarly to Japan-Malaysia initiatives under the LEP, the National Cancer Society of Malaysia (NCSM) and the Asia Cancer Forum (ACF) of Japan are working together to elevate human security in terms of prevention and early detection of cancer.

Today's talk relates to disparities in the Malaysia cancer care landscape, including specific disparities that hopefully under the new government can be worked on, with a view to ameliorating or resolving them.

Malaysia's formal healthcare system is divided into two distinctly separated sectors, the public sector, which is taxpayer funded, and the private sector, which is funded by private insurance and out-of-pocket paying patients. One of the major issues in Malaysia is that the public and private sectors are not aligned. Because of that there are major disparities in terms of the level of healthcare that is provided. The majority of Malaysians (over 65%) use the public sector healthcare system. The pandemic has also boosted use of the public healthcare system in Malaysia. There are over 1 million foreign workers in Malaysia, many of whom also use the public healthcare system.

In terms of healthcare personnel, Malaysia currently has 71,041 medical doctors across the public and private sectors, equivalent to one doctor for every 454 people, and 73 percent, or 51,912 doctors are working in the public health system. However, the healthcare delivery system is not evenly distributed across states, due to rural disparities, geographical challenges, socioeconomic factors and medical tourism among other factors. Whereas the Klang Valley (Kuala Lumpur region) has 99.6 doctors per 100,000 population, Sabah State has only 33.4 doctors per 100,000 population. This underscores the tremendous difference across the country.

In terms of institutions providing cancer care, the disparities are similar to the overall healthcare picture, with most cancer-related care being concentrated on the west coast of peninsular Malaysia. Cost-effectiveness pressures have pushed services to areas of high density populations. If patients have to travel far from their homes it tends to lead to late diagnosis, or intermittent treatment of disease. The question arises, therefore, as to why hospitals and clinics are not more evenly spread and cancer care coverage is sparse to non-existent in some areas. In East Malaysia there are issues of inaccessibility, but there

are large swathes of the two states that have very little healthcare delivery.

(2) Introduction and challenges to the Malaysian cancer landscape

In Malaysia, cancer control remains a complex, multi-dimensional issue. The cancer control continuum concept has been in use since the 1970s and has been a good tool, but it does not really show the complexities of cancer control and how they can be addressed. The cancer control continuum helps to identify gaps and areas for collaboration.

A key challenge in Malaysia is the disconnect and non-continuity between the public and private healthcare sectors in terms of provisioning, with regard to diagnostics, treatment and palliative services in cancer. The issue with the private healthcare sector is that there is no monitoring and evaluation and so there is no data to demonstrate outcomes and quantify whether the extra financial outlay results in better outcomes. There needs to be better monitoring in this regard.

Prior to the global pandemic there was uncertainty relating to the health system amidst economic turmoil and an incapacity to cope with rising disease burdens, long courses of treatment and the continuous demand to provide access to newer, lifesaving therapeutics. There is inequity in access to early detection and timely treatment for the lower socioeconomic groups, with mounting financial concerns to patients and their families looming large over the cancer landscape.

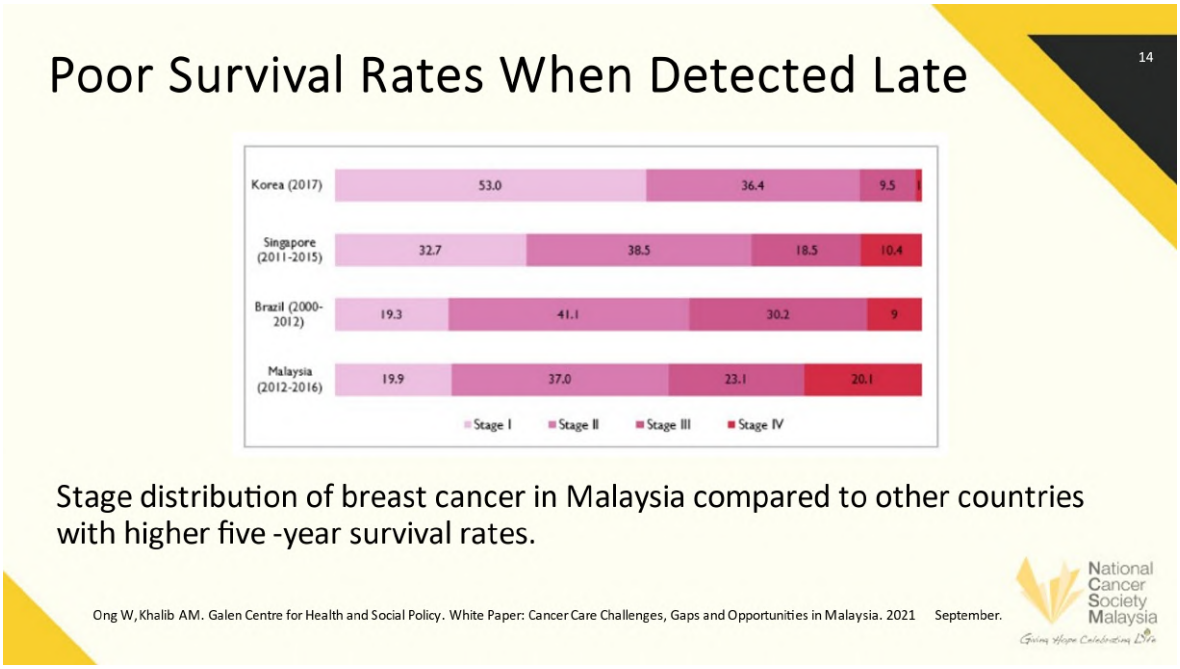
The turmoil in the health system in Malaysia results in delays in diagnosis and late presentation within Malaysian patients, resulting in poorer outcomes and higher treatment expenditures both at a micro and macro level. Large, crippling catastrophic debts are borne by patients and caregivers and there are long, indefinite periods of maintenance therapy with life-saving yet highly expensive innovator drugs.

(3) Financial, economic and social impact of cancer in Malaysia

So, how does late diagnosis and financial impact affect the individual and the community? As an example, the following slide shows the poor survival rates of breast cancer when detected at a late stage.

As can be seen on the slide, in countries like Korea and Singapore, where screening services are highly formalized and national based, the rate of early detection is much higher than in Malaysia, where screening is more informal and run by organizations such as NCSM, making screening initiatives piecemeal.

Figure 1: Survival rates of breast cancer in Asian countries

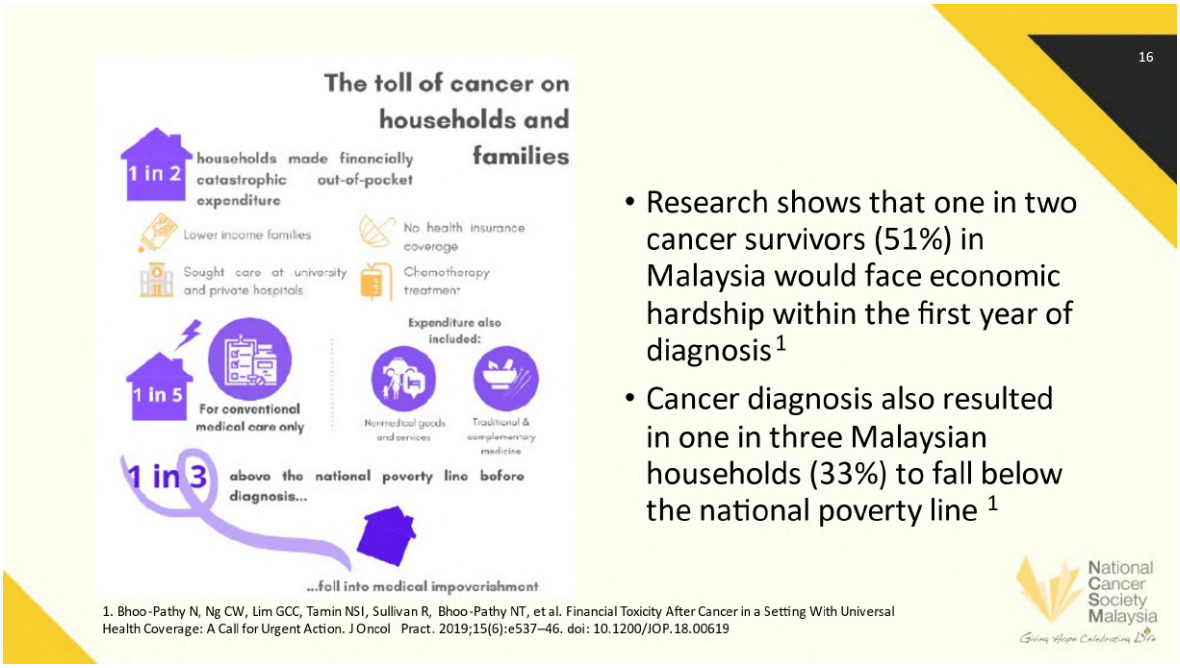


The low number of stage 1 cases detected is not just reflective of the services that are in place in Malaysia, it is also reflective of behavior. Without health-seeking behavior in place it will not translate into people coming to use the services available. Health literacy is therefore a key challenge, both in the general populace and also among health professionals.

Financial toxicity refers to problems a cancer patient has related to the cost of treatment. Once diagnosed with cancer, patients often face and long and arduous journey to access care, begin and complete treatment, and adapt to survivorship. On top of financial challenges, navigating the cancer care pathway from screening, diagnosis, treatment, and support care, are often fraught with logistical, informational, emotional and system barriers. By having patient navigation protocols in place it is possible to support patients on their cancer journey. This is where the NCSM is rolling out patient navigation systems throughout Malaysia in order to fill the gaps that exist, down from the hospital level to the community level.

At the present time, one in two cancer survivors will face economic hardship within the first year of diagnosis. Cancer diagnosis also results in one in three Malaysian households falling below the national poverty line.

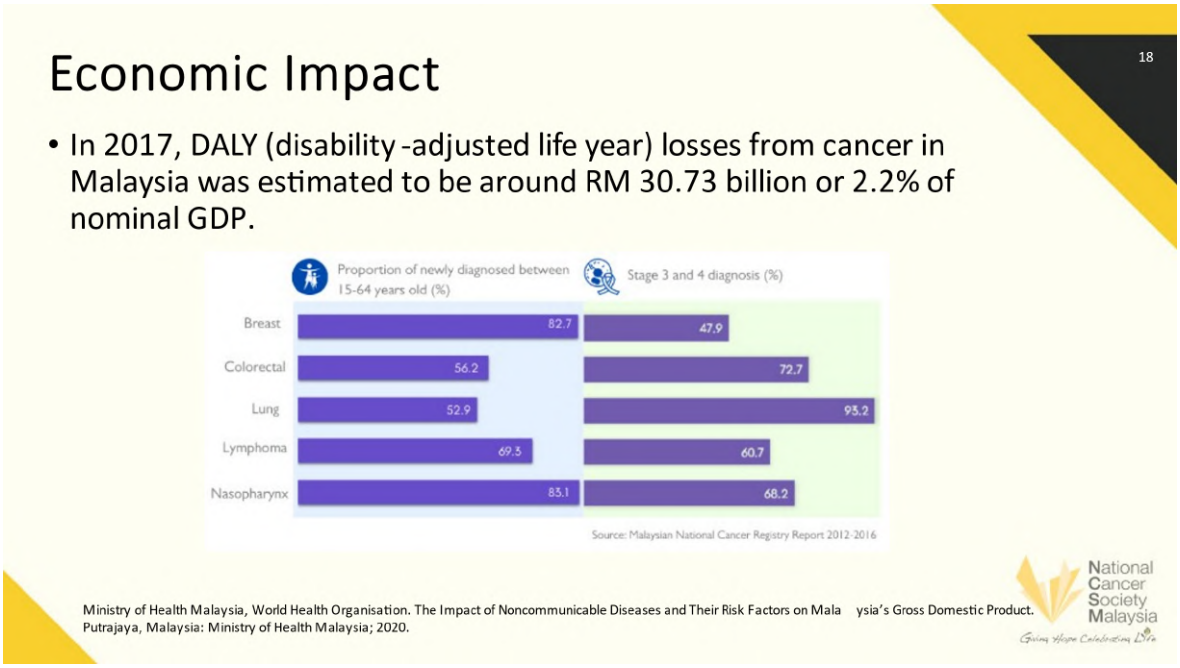
Figure 2: Toll of cancer on households



Other out-of-pocket expenses that affect survivorship include hospital follow-ups, parking fees, transport fees, childcare fees and lodging fees.

In terms of the economic impact of cancer, in 2017 DALY losses from cancer in Malaysia was estimated to be around RM30.73 billion, or 2.2% of nominal GDP. The reason this figure is so high is that cancers are found in younger people in Malaysia.

Figure 3: Economic impact of cancer in Malaysia



A large proportion of cancer patients are also diagnosed during their most productive and economically active ages. This highly affects the economic productivity of a country. Many employed individuals are unable to continue working due to prolonged work absence, lack of workplace flexibility, and reduced productivity while going through treatment. Regardless of initial socioeconomic status, loss of income and unemployment after a cancer diagnosis are major causes of financial hardship. The choices are often stark: stay home and retain your job or get treated and lose at least several days' worth of wages or even become unemployed.

In terms of the social impact of cancer and the gaps between the public and private sectors, self-paying patients seeking diagnosis in the private sector may experience delays due to fee payment, insurance coverage, or the time-off needed for employer approval. Out-of-pocket expenses are also far more expensive in the private sector, but are still chosen due to the delays and long waiting times in the public sector. There needs to be more collaboration and alignment between public and private healthcare systems to promote more seamless navigation for patients. Survivorship gaps also exist, with many facing long-term physical side effects, psychosocial distress, and financial hardship. Cancer patients also experience losses in income and productivity, limits to daily activity, and costs in time and transportation needed to access regular medical care. Families face financial struggles and there are also barriers to governmental financial support, some of which depend on the state/district in which patients live. There needs to be greater consistency with regard to financial support across all states in Malaysia.

(4) Actions to ameliorate the impact of cancer

In terms of actions to reduce the impact of cancer, more people need to be screened and diagnosed at an earlier stage of their cancer when treatment is most effective, and the chance of survival is at its highest. Some of the work done by NCSM is to encourage early screening for early cancer detection.

In addition, timely, effective and innovative treatment should be made available when it is needed to avoid the burden of undertreated cancer. Not all cancers can be detected early, and the health system must not leave behind those diagnosed with advanced cancer.

The financing and governance of cancer care also needs to be optimized to steer towards better survival, reduced burden from cancer, and overall better health outcomes.

As mentioned by Ambassador Takahashi, health goes way beyond just looking at the well-being of our bodies, it represents the security of the human being too, and therefore all areas of the SDGs that impact health require attention.

One of the programs being implemented in Malaysia is the NCSM-ETIQA program for breast cancer screening and detection. This program has helped to boost screening levels nationally.

The Bringing Education And Understanding To You (BEAUTY) Program is an international collaborative project between Malaysia and Japan that addresses the system gaps such as poor health education, literacy and awareness, and proposes a solution via community empowerment at local barbers and beauty salons.

In conclusion, healthcare in Malaysia is divided into public and private sectors. There are distribution, density and socioeconomic disparities that affect the cancer care landscape, and gaps exist with the cancer care continuum in Malaysia that causes devastating effects financial, economically and socially. Health therefore needs a “whole-of-society” approach with multisectoral collaborations.

Discussion

Q: I was interested to hear about the healthcare system in Malaysia and the lack of alignment between the public and private sectors. Do people with sufficient money go abroad for treatment? Also, is the private healthcare sector run along business lines, rather than for human security and human well-being?

Saunthari: The private healthcare sector in Malaysia started up in the 1980s and there was a thought at the time that private healthcare would complement the public healthcare sector. However, private healthcare wasn’t monitored and there was no oversight. The private healthcare sector then became a business, particularly so with cancer. Cancer is the fastest growing healthcare sector in private hospitals in Malaysia. The unfortunate part of this whole thing is that it causes a stigma with regard to public healthcare treatments, where in many cases the public healthcare teams provide care that is certainly equal to the standard of care in private hospitals. The private sector needs better monitoring and evaluation to see whether the provision of healthcare is to the standards that are acceptable and within guidelines on cancer treatment. I am optimistic that the public and private sectors can work together, with the ETIQA program being one example. There are

ways and means of working together and more should be done to identify them.

Sonoda: The disparity between the public and private sectors in Malaysia is something that is seen in other countries too, but the message about the importance of early screening and detection is one that is universal. This is something where there is room for cooperation between Japan and Malaysia.

Saunthari: It has been recognized by the Ministry of Health and the government that more needs to be done to respond to the increasing disease burden in an aging society. There is much that can be learned from Japan in this regard.

Lecture No.9

Introduction to the BEATY and Health Project

Murallitharan M.

Managing Director, National Cancer Society Malaysia (NCSM)

(1) Introduction to the lecture

Dr. Kawahara noted that during the lecture series students had been learning about UHC for cancer in Malaysia. The final goal of the lecture series is for students to present their recommendations about the BEAUTY and Health Project. It was explained that Dr. Murallitharan would present an overview to the BEAUTY Project in this lecture. The following week a series of awareness-raising videos will be shared among students. These videos will help students get a better understanding of the various initiatives being advanced in Malaysia.

Dr. Murallitharan noted that during the previous weeks, aspects of the BEAUTY Project had been discussed and he hoped to put into perspective some of the material relating to the project.

(2) Malaysian cancer treatment journey: Prevention

In terms of the Malaysian cancer treatment journey, various people have spoken in this lecture series about the cancer treatment structures in Malaysia, the most fundamental of which is the cancer care continuum. The continuum comprises various aspects. First, through prevention the aim is to promote population health and well-being and prevent disease and harm before it occurs. Prevention comprises various aspects, including nutrition, exercise and not smoking, etc.

An issue that is faced is that very few governments around the world put money into prevention, and because it does not have a curative aspects, ministries other than health ministries may be involved in prevention-related activities, including education ministries, etc. This is the reason why prevention in health takes a social determinants of health-type approach. Social determinants of health means that there are many factors that influence health, but they may have little to do with health directly. For example, in Tokyo there is a very good public transport system, and individuals are de-incentivized from going into Tokyo using their own vehicles. The unintended benefit of the broad use of the public

transportation system in Tokyo is that people are forced to walk, either intentionally or unintentionally. This is an indirect mechanism to promote population health, by making people do their 10,000 steps a day and be physically active. This type of intervention has nothing to do with health, but it has a very indirect promotive benefit on the health of the population.

In the case of Kuala Lumpur, although there is public transportation it is not adequate enough to encourage people to use it comprehensively, which is why people still choose to drive their own vehicles (cars and motorcycles). The negative effect of people using their own vehicles is that people do not feel the need to walk, as they are always using their own vehicles. Public transportation is therefore a policy that can have preventive effects for health.

Another area that has an impact on health while being unrelated to health is urban planning. The built environment around individuals can optimize their ability to use that environment for exercise and relaxation. Mental health plays a huge part in cancer, so the built environment and relaxing spaces have a significant role to play in that area.

These examples illustrate that funding for prevention does not necessarily have to come from health ministries, as policies relating to transport and urban planning are sourced from elsewhere.

(3) Malaysian cancer treatment journey: Screening

In terms of screening, the aim is to find diseases at an early stage when there may be a better chance of curing the disease. Examples of cancer screening tests are the mammogram, colonoscopy and the Pap test and HPV DNA test. In order to get a person interested in screening it is necessary to encourage such behavior. In countries like Malaysia where testing has to be paid for by users there has to be a desire to actually pay for a test in the interests of health. This requires greater awareness about the importance of screening being disseminated among the population.

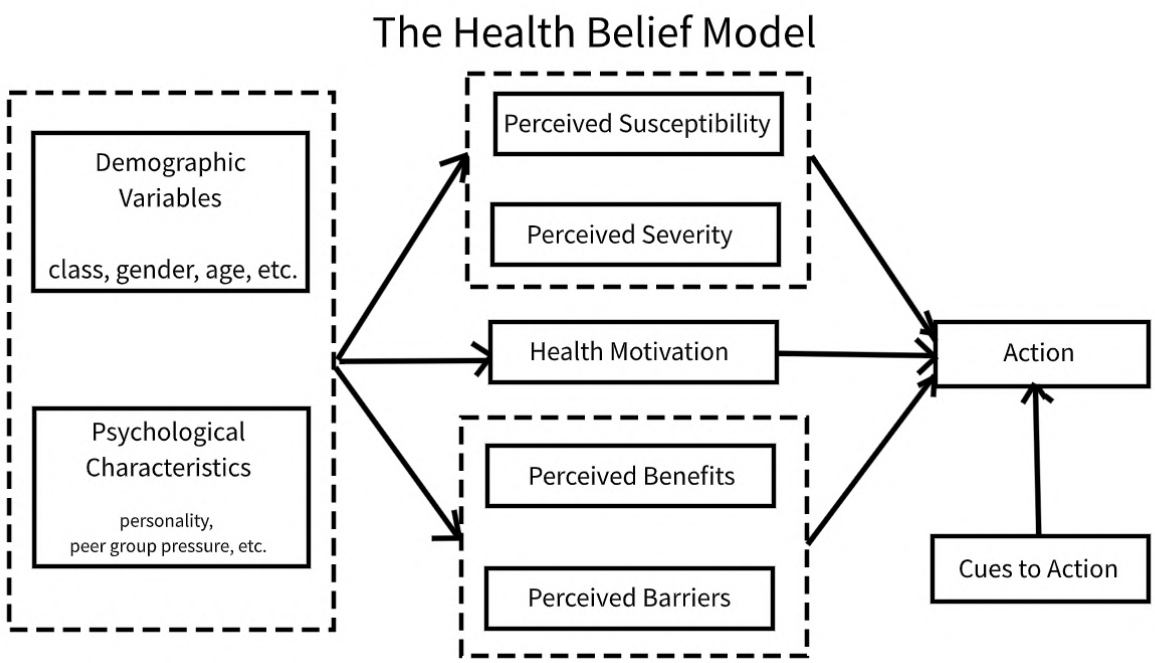
Screening is something that needs to be done regularly throughout a person's life, and this makes it something that is even more challenging for people, particularly those who have to pay for screening. It is important to encourage a mindset that is inclined to go for screening. The "Health Belief" model is one way in which this can be realized.

In the "Health Belief" model there is a concept that there is always why people do what they do. People are only going to take an action pertaining to health if the following criteria

are met: perceived susceptibility, perceived severity, health motivation, perceived benefits and perceived barriers.

In terms of perceived susceptibility, a person has to be made to understand that as a human being there is a risk of getting cancer. In order to create Health Belief, it is necessary to inculcate an idea of perceived susceptibility, only then will people be interested in taking health actions.

Figure 1: The Health Belief Model



The next criterion is perceived severity, namely that people understand that cancer will affected them severely. If there is a possibility of being severely affected, this can prompt people to take action in the form of screening. For example, COVID-19 is perceived as being very dangerous, which is what prompts people to seek help (in the form of vaccination) because they realize the elevated risks they face.

The third criterion is health motivation, which is related to a person's individual motivation. Individual motivation is influenced by the people around you and the more people are motivated in terms of health, the more likely they are to take action. One of the most effective health motivating factors is when a loved one dies. A person can also be motivated through modelling. Another way to increase extrinsic motivation is to operate a program that incentivizes people to participate in screening.

The fourth and fifth criteria are perceived benefits and perceived barriers and it is equally important for people to understand the potential benefits of changing behaviors and receiving screening. In terms of perceived benefits, if a person believes that taking certain actions will benefit their health, they will be incentivized to take action. Perceived barriers means an understanding of the constraining factors to health-improving actions. People need to be able to perceive that the benefits will outweigh these potential barriers.

The BEAUTY and Health Project functions across all these five criteria.

(4) Malaysian cancer treatment journey: Diagnosis, treatment and survivorship

In terms of diagnosis, the aim is to find cancer at the earliest stages and often provides the best change for a cure. Diagnostic procedures for cancer may include imaging, laboratory tests, tumor biopsy, endoscopic examination, or genetic testing. For treatment, the goal of cancer treatment is to achieve a cure for cancer, allowing the patient to live a normal life span. Survivorship focuses on the health and well-being of a person with cancer from the time of diagnosis until the end of life.

(5) BEAUTY and Health Project overview

Over the past weeks the lecture series has been discussing the BEAUTY and Health Project. In essence the project comprises three phases: 1) the development of a structured intervention comprising of health educational materials and content for the BEAUTY program, as well as a training module for the barbershop and beauty salon “change agents,” (2) development of an online, open access cancer screening and health assessment resource registry for males and females, focusing on the main screen-able cancers for males and females, and (3) seeking to encompass the actual deployment of the intervention on the ground.

Through the BEAUTY and Health Project the aim is to intervene in barbershops and beauty salons, which are places where people go for monthly haircuts. Barbers are being trained to speak to customers about the importance of preventing cancer as well as encouraging them to pick up and read prepared materials. The idea is that people will be more disposed to going for screening if encouraged to do so by their barber / beautician, who is someone who is close to them in their daily lives.

In phase 2, the project will seek to develop an online health assessment resource app, which will then be rolled out in phase 3 in order to test efficacy.

The idea is to implement interventions on a monthly basis for six months and assess how the barbershop / beauty salon interactions have impacted a person's actions in seeking cancer-related information or screening.

BEAUTY and Health Project is focused towards the prevention and screening aspects of the cancer treatment journey, as well as diagnosis to a certain extent.

Under the BEAUTY and Health Project it is assumed that individuals visiting barbershops and beauty salons have no knowledge about cancer. It is also assumed that customers have a long and trusting relationship with the barber / hair stylist, who has the power to exert influence on their customers. In this way the barber / hair stylist is becoming the instrument of health motivation. Information provided via the app that is being developed will include information on perceived susceptibility, perceived severity and provide health motivation, as detailed in the Health Belief Model. Efforts will also be made to overcome perceived barriers. For example in rural areas there may be no hospital or clinic nearby, but under the project it may be possible to arrange for transportation to the hospital or clinic for screening, thus eliminating the perceived barriers. The overall aim is to drive action among the individuals who visit the barbershops / beauty salons.

As described above, the BEAUTY and Health Project is also targeted towards changing individuals' behavior.

(6) Considering how to enhance the BEAUTY and Health Project

The BEAUTY and Health Project is a large-scale intervention project that seeks to raise awareness about perceived susceptibility and perceived severity, as well as helping to ameliorate perceived barriers.

Lecture series students are tasked with coming up with suggestions to enhance the project. Questions to consider are how to improve understanding about perceived susceptibility and perceived severity with regard to cancer.

Students are also asked to come up with proposals that can provide health motivation to individuals. Are there any micro-interventions that could be implemented to help and encourage individuals to take appropriate actions?

It is hoped that students will provide very specific suggestions for enhancing the BEAUTY and Health Project.

Discussion

Dr. Kawahara noted that some students may be watching the lecture in an on-demand format, so questions could be forwarded to Dr. Murallitharan after the lecture.

Q: I understand that there are some barriers to screening and diagnosis in Malaysia, but in terms of accessibility, where do people normally get information about where they can receive screening?

Murallitharan: Technically, Malaysians can visit their primary healthcare clinic, where they can receive cursory tests, such as a breast examination. If something is found to be wrong they will be referred to a public hospital. However, there are long waiting times in the public health system, even though the service is free. However, in reality, due to under resourcing people go through the private healthcare system to receive scans. There is no standard website or portal that tells people where they should go to receive screening/testing. Instead, private hospitals advertise their services. There is no comprehensive mapping of where you can go to receive screening. NCSM has developed a map of facilities around Malaysia where screening services are provided. This map is available on a website that also features various vouchers that provide a discount for cancer screening. Although this service does not cover all hospitals, it is an attempt to provide information on screening availability.

Q: Are people who go to receive screening symptomatic or not?

Murallitharan: Almost 60% of all cancers in Malaysia are discovered in Stage 3 or Stage 4, so this suggests that most people are going to screening presenting with symptoms.

Q: In this BEAUTY Project a smartphone app is going to be used to promote the project, but will this not raise issues of IT literacy among older people?

Murallitharan: One in three adults have low health literacy and a cancer literacy questionnaire is also being implemented currently. Health promotion materials are going to be distributed through multiple channels. The first channel is mainstream media, and advertisements are going to be placed on commuter trains, as well as buses and subway

systems. Messaging concentrates on getting people to become more interested in their perceived susceptibility, as well as appreciating perceived benefits.

Also, through mainstream newspapers there are plans to carry health promotion materials.

In addition, outreach via television and radio is being planned, which will include information about the BEAUTY and Health Project.

In order to promote uptake of the app, efforts will be made to encourage children to download the app for their parents, who may have lower IT literacy.

In another development a major advertising agency has agreed to promote the BEAUTY Project on its electronic billboards.

Q: How will the barbershops and beauty salons be selected? Will rural areas be selected? Also, how will barbershops be persuaded to put up posters about cancer, which can be perceived as a very negative topic?

Murallitharan: The aim is to give the barbershop / beauty salon workers motivation to become “change agents.” They will be provided with training to interact with customers and raise awareness about cancer. They are being asked to play a role in helping a national effort to improve cancer screening. They are also being provided with a small incentive to promote registration of their customers on the app. In addition to these efforts, barbershop / beauty salon owners and staff will be provided with cancer screening for free. The barbershop / beauty salon venues will also serve as a base for screening activities in the future.

With regard to encouraging participation, it is inevitable that some people will not be interested, but efforts need to be made to enhance people’s responsiveness and acceptance of the project.

In the pilot testing phase both urban and rural areas are being targeted, and in urban areas the key targets are the urban poor.

Q: With regard to the question from another participant about barbershops / beauty salons not wanting to talk about cancer, in a recent set of interviews with various potential cooperating barbershops / beauty salons there were some shops that were very positive about cooperating, particularly those in high-end urban areas. In contrast, some other

stores were reluctant to engage with their customers about the topic of cancer, because they are worried that customers would be put off by this potentially difficult topic. This reluctance is seen more predominantly in less affluent areas.

Murallitharan: The challenge will be to engage with various communities. In many cases beauty salons are run by ethnic-Chinese people, with customers coming from all ethnic backgrounds. Some upper-middle income groups that are religiously conservative may be averse to talking about cancer, but efforts need to be made to work with the various outliers.

Q: When deploying the project to specific religious, ethnic or age groups there may be some people who are resistant to changing their ideas, even when encouraged to do so. What can be done to persuade these people?

Murallitharan: We need to recognize that there will never be a 100% success rate in reaching out to people, so the app will concentrate firstly on the 50-60% of the population who are most responsive. The important thing is to first roll out the app and the project in order to assess its effectiveness and take-up. The materials have already been created for the project in four different languages and using four difficult cultural contexts.

Dr. Kawahara thanked all participants for their input and active engagement with the class.

Lecture No.10

Believe in the power of BEAUTY (Bringing Education and Understanding To You): A community-based intervention program aimed at improving cancer-specific health knowledge, literacy and risk-reduction practices

Norie KAWAHARA
Project Associate Professor, Institute for Advanced Studies on Asia (IASA),
The University of Tokyo
Representative Director, Asia Cancer Forum

(1) Introduction to the BEAUTY and Health Project

In her lecture Dr. Kawahara explained the details of the recently launched BEAUTY (Bringing Education and Understanding To You) and Health project and the history of similar projects and the rationale behind their implementation in the diverse region of Asia. The BEAUTY and Health Project in Malaysia is being supported by Astellas Pharma Inc., under its *Access to Health* initiative.

This project is a cancer control activity program that includes cancer awareness in the community through barbers and beauticians, building a cancer prevention registry and developing a cancer education database, etc. It is planned to be implemented in Malaysia for three years in collaboration with the National Cancer Society of Malaysia, the Asia Cancer Forum and Astellas Pharma Inc.

Before explaining the details of the current BEAUTY and Health Project, Dr. Kawahara began with an introduction to the Asia Cancer Forum, one of the implementing bodies of the project, and also provided details of the case of community-driven awareness-raising programs implemented previously in rural China.

(2) Introduction to the Asia Cancer Forum

The Asia Cancer Forum (ACF) was established in 2004 as the Asian Cancer Information Network. It changed its name to its current form in 2008 and since then has continued to implement various activities.

The overarching vision of the ACF is “Surviving Cancer in Asia” and to realize this vision its stated mission is as follows:

"The Universal Declaration of Human Rights states that everyone has the right to share in scientific advancement and its benefits equally. Based on that spirit enshrined in the Declaration, with the aim of overcoming the common challenge of cancer that is faced by humanity as a whole, and linking it to human life in the Asian region, we have attempted to bring together several types of "intelligence," which we have subsumed as the "3Cs": Collective Intelligence, Contextual Intelligence, and Continuous Intelligence."

The ACF aims to engage in the following actions: 1) implementation of cancer care that leaves no-one behind, 2) Livelihood-based research and multilayered perspectives through the use of information technology, 3) Surviving with cancer, the ancient connection of the land, and a recycling-oriented symbiotic infrastructure, and 4) the formulation of international proposals that transcend public-private and interdisciplinary frameworks, centered on the shared challenge of cancer.

Since its inception the ACF has focused its efforts on the health agenda in Asia, particularly in the context of realizing universal health coverage (UHC) for cancer care in Asia. Together with regional and international institutions, ACF has sought to encourage and invigorate collaborations, both between researchers and among academia, industry and government.

While recognizing that cultural diversity in Asia may be an obstacle to overcoming cancer, this cultural diversity in itself is also a tremendously powerful force. The ACF considers it to be important to carefully bring together the various societies in Asia and seek to address the various different views and perceptions regarding cancer in the region.

(3) Healthcare education project in Harbin City, Heilongjiang Province as the forerunner for the BEAUTY and Health Project

The origins of the BEAUTY and Health Project date back to healthcare educational projects implemented in Harbin, China, the first of which was launched in 2005. A Japan International Cooperation Agency (JICA)-funded project to engage in grassroots assistance was implemented from 2014 to 2017. This project, summarized below, suggested the necessity of implementing similar research in other countries in Asia.

Heilongjiang Province is a predominantly rural area that is subject to extremes of temperature and lags behind other regions of China in terms of economic development. As

such there are major health disparities between Heilongjiang and other provinces. Initial research was based on a desire to find out about what people in this rural region of China think about cancer.

This research was informed by comments made by the scholar Christopher Cheng in 2009 that:

> *"Culture affects both the risk factors for cancers and the meaning of the disease by influencing the behavior responding emotionally, cognitively and socially to this disease….Culture will determine approaches to prevention, early detection, treatment choices, and management of side effects such as pain, appropriate psychosocial support, rehabilitation efforts, survivorship issues, hospice use and effective end of life care."*

The JICA project targeted elementary and junior high school students and their parents. The children were first targeted by using a DVD-based educational video, and their parents or guardians were subsequently questioned about the child-to-parent feedback on the classroom lesson, as well as about lifestyle, awareness, and prevention. The questionnaire consisted of 24 pertinent questions, including two personal information questions (age group and sex). Answers were collected from 287 respondents and subsequently analyzed. The questions were first analyzed in relation to respondents' age group and sex. Then the answers were inspected using correlation analysis (Spearman's Rho) to see whether there were any patterns in respondents' attitudes. For questions with strong correlation, Chi-squared analysis was then implemented.

One interesting finding in China was that older generations had a tendency to believe that lifestyle practices or changes can help prevent cancer. As cancer education has been uncommon for all generations in China, the tendency is not a result of school education but should be considered to be a result of life experience, especially empirical rules resulting from daily observations regarding lifestyle and cancer diagnosis. This question certainly requires follow-up surveys in other countries to see whether it is a distinctly Chinese trait, Asian trait, or some sort of basic human behavior.

In terms of gender, the only visible difference was seen in terms of lifestyle priority. Female respondents had noticeable priorities in securing enough physical rest and a nutrition-balanced diet, whereas male respondents prioritized cutting down on smoking and drinking. Possible reasons may be attributed to differences between genders in smoking and drinking, daily work schedule, and family-chore responsibilities. This trend

should be similar for other countries, but percentages would vary highly due to national differences in work-life balance and gender roles.

Another gender-related difference was observed in respondents' attitudes towards making decisions in terms of cancer treatment. Far more female respondents wished to discuss matters with family members than male respondents. This may also be a transnational, basic gender-influenced trait, although the degree of family dependency would vary greatly by culture and ethnicity.

The project in Heilongjiang Province provided a valuable opportunity to implement patient engagement activities in the community. The shift from traditional models of healthcare delivery to community-focused models is imperative for the realization of UHC. Another imperative is the development of low-cost systems that will enable and encourage people to manage their own health.

(4) Project outcomes point to future research themes

The project in China highlighted the fact that Asia is a region with unique difficulties for providing uniform measures for cancer control and treatment, due to significant disparities in medical and healthcare standards and regional cultural diversity. Furthermore, it is not enough to merely identify the many socio-cultural impacts upon prevention, screening, diagnosis, disclosure, therapeutic decisions, and palliation of cancer; it is also important to discern the socio-cultural influences by factors such as nationality, ethnicity, race, religion, beliefs, ethics systems, and geography. The project concluded that in the future it would be important to seek to: 1) Identify differences and commonalities in the perception of cancer, 2) Assess individual and shared needs, and 3) Use the results as a barometer for cultural attitudes and social systems relating to cancer.

(5) Lessons from the project in China

During the project in China, there were a few areas where project implementation did not go according to the initial plan. One of these was the initial attempts to raise awareness with local public experts, which were of only limited success.

It was this limited success with using local experts that prompted the project team to turn to local beauty salons to take on an awareness-raising role. The rationale behind this move was that beauty salons are places where local people visit on a regular basis, and hairdressers and beauticians have interpersonal skills with their clientele.

The beauticians were asked to form a group centered on the local women's association. The project team distributed information on both beauty and medical check-ups, and also provided a beauty course using products from a well-known Japanese cosmetics brand. The prospect of receiving beauty advice and testing products provided an incentive to people to attend the course, with the local beauticians taking a central facilitating role.

The use of beauty salons as an entry point to the local community led to the creation of various networks, and also enabled the project team to reach out to young mothers about the value of good health, the importance of prevention and the availability of cancer screening programs.

One of the major challenges faced was the widespread image of cancer as a "death sentence," that of a fatal disease from which people cannot recover. It was therefore important to share information about survivorship and emphasize the critical importance of early diagnosis. Such stories were provided by people from within the community or network, who had their own survivor stories to share.

The use of beauty salons in rural China showed that such local touchpoints are a valuable means of reaching out to residents and encouraging them to receive screening and check-ups. The project found that the rate of behavior change was high only when people were able to communicate with relatable people in their own communities and get a concrete picture of the message. Although perhaps a cliché it is true that to move people it is necessary to reach out to their hearts as much as their minds.

In the activities in the rural villages of northern China there was a strong sense of how positive reinforcement and optimism have the power to change people's lifestyles and habits for the better. Social implementation activities using the power of "beauty" also have the potential to support sustainability. What is important is to provide value to people at the best possible timing, with the best possible contents, and best-suited communication methods. To understand the pain points in people's individual situations and the self-realization they want to achieve, it is important to have frequent and regular contact with the people you are seeking to help.

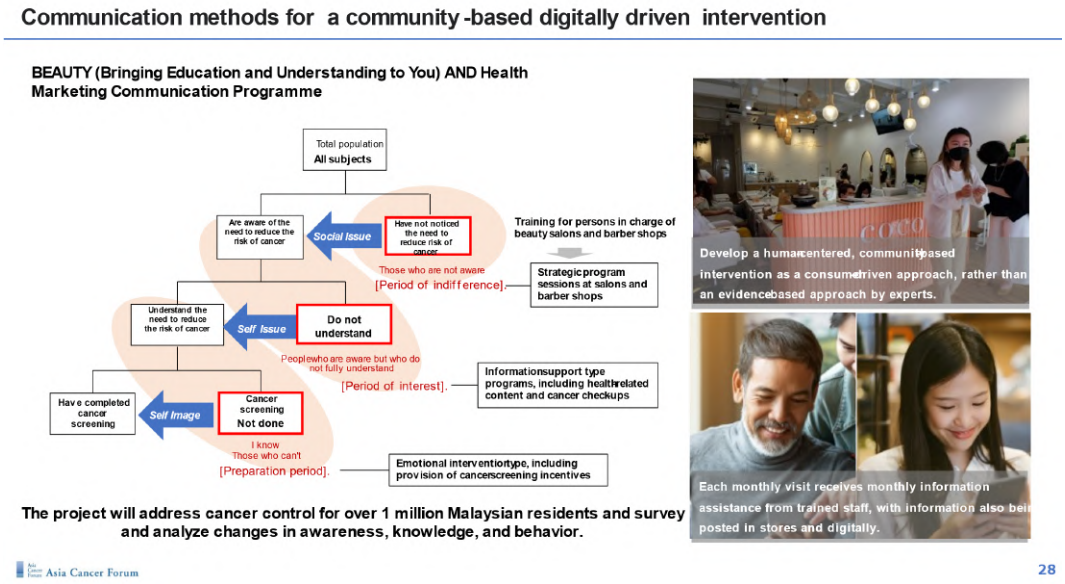
From that perspective, barber shops and beauty salons are undoubtedly one of the best-positioned places of interaction for maintaining such regular and frequent contact in the community.

(6) Launching the BEAUTY and Health project in Malaysia

It is these experiences in China that gave momentum to implementing a similar project in Malaysia. In multi-ethnic Malaysia, more than 60% of cancer patients are diagnosed at an advanced cancer stage (stage 3 or 4). Many of these patients have little or no access to treatment or knowledge about prevention. As a result, the level of health-related education and health literacy is inadequate. Many cancer patients also have financial problems that make it difficult for them to continue regular treatment.

The BEAUTY and Health Project will support cancer control efforts through a program by the National Cancer Society of Malaysia (NCSM) and the Asian Cancer Forum (ACF), with the support of Astellas Pharma, Inc. The program aims to build a database for cancer education, which patients can use to obtain advice on cancer screening specific to men and women. Patients who register on the 'Malaysian Cancer Prevention Registry Portal' can also use the site to assess and manage their own health risks. In addition, community engagement sessions for cancer disease awareness will be held in local barber shops and beauty salons frequented by local residents.

Fig. 1 Image of how communication methods will be implemented for a community-based digitally driven intervention



Advances in digital technology have made it possible to access not only people's attribute data, but also data about their thoughts and behavior, which offers the potential to get a clearer picture about individuals. Interest in and precision of patient segmentation is

already increasing. Not only will this be critical to resolving health inequalities, it will also be important for eliminating waste and targeting resources in order to improve outcomes. As marketing methods have demonstrated for years, segmenting groups of people is consistently shown to be superior to a one-size-fits-all approach. It is this this one-size-fits-all approach that particularly fails those who have most to benefit. Individualized communication is recognized to be an essential method to help to change behavior. Therefore an app-based approach using salons and barber shops in the community is expected to be an effective means of deployment.

As shown in the figure below, people's attitudes to cancer screening can be anticipated to fall into one of five phases:

Fig. 2 Phases of understanding and engagement with screening and checkups

Condition and effective strategies for each phase

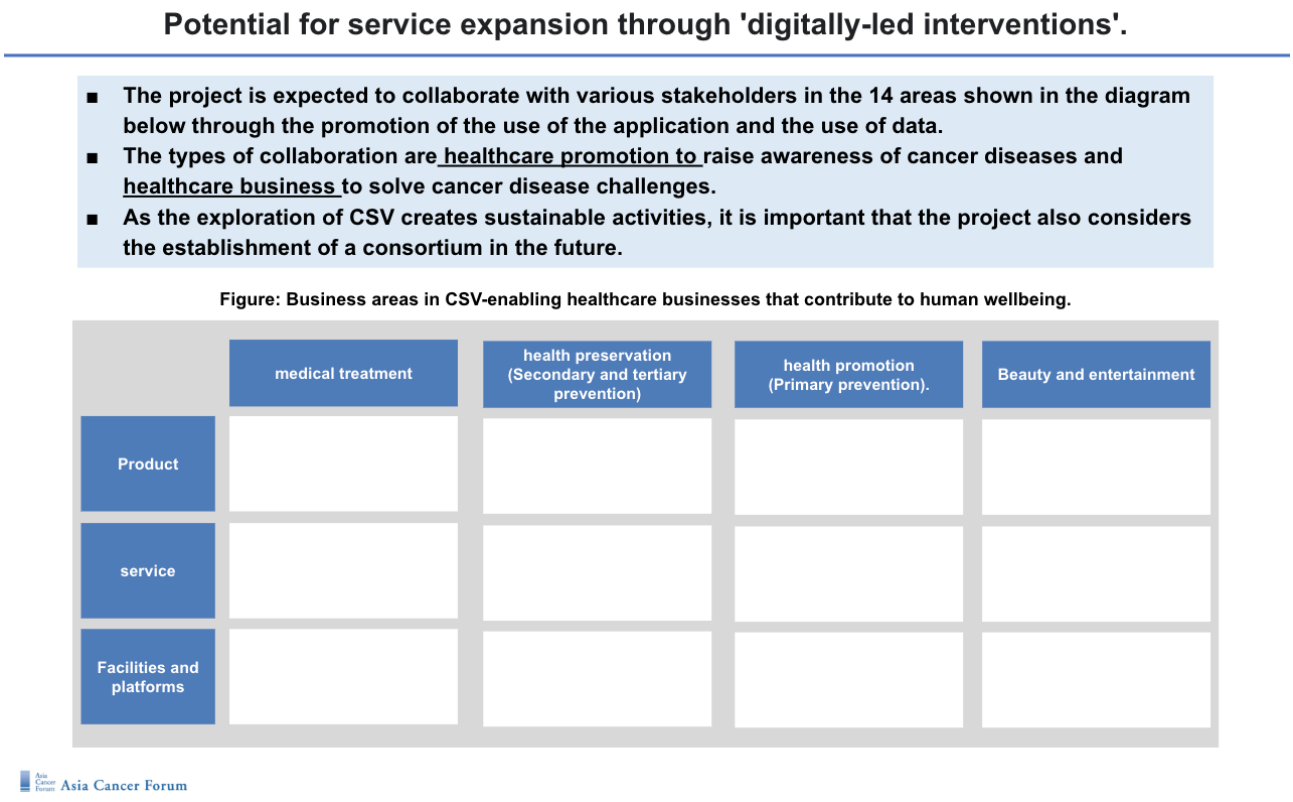
Phase	Condition	Effective strategies
Precontemplation	I have some knowledge but do not understand the necessity.	Provide more information according to each individual about the risk and benefit and increase the acknowledgement of needs.
Contemplation	I am interested in having a checkup but neither do I have enough incentive to take action nor a sufficiently enabling environment.	Provide incentive. Recommend making specific action plans.
Preparation	I understand the necessity but do not have checkups.	Support making clear action plans and carry them out. Set goals, little by little.
Action	I have had checkups before but have not continued.	Support by giving feedback, problem-solving methods, social assistance, reinforcement.
Maintenance	I am continuing to have checkups.	Support by coping, reminding, finding alternative means, preventing mistake and backtracking.

National Institute of Public Health of Japan, Theory at a glance : a guide for health promotion practice, 2008

For the purposes of the HEALTH and Beauty Project, the plan is to focus initially on people who are in the "contemplation" phase, who are aware of cancer and the importance of cancer risk reduction, but have not yet felt motivated or incentivized to receive screening for cancer. It is for these people that an app-based digital-led intervention is to be implemented for screen-able male and female cancers.

After the initial deployment to people in the "contemplation" phase, it is hoped that the project can be expanded to encourage collaboration among various stakeholders in the 12 areas detailed in Figure 3, through the promotion of the use of the app and the utilization of data collected.

Fig. 3 Twelve areas for collaboration among stakeholders

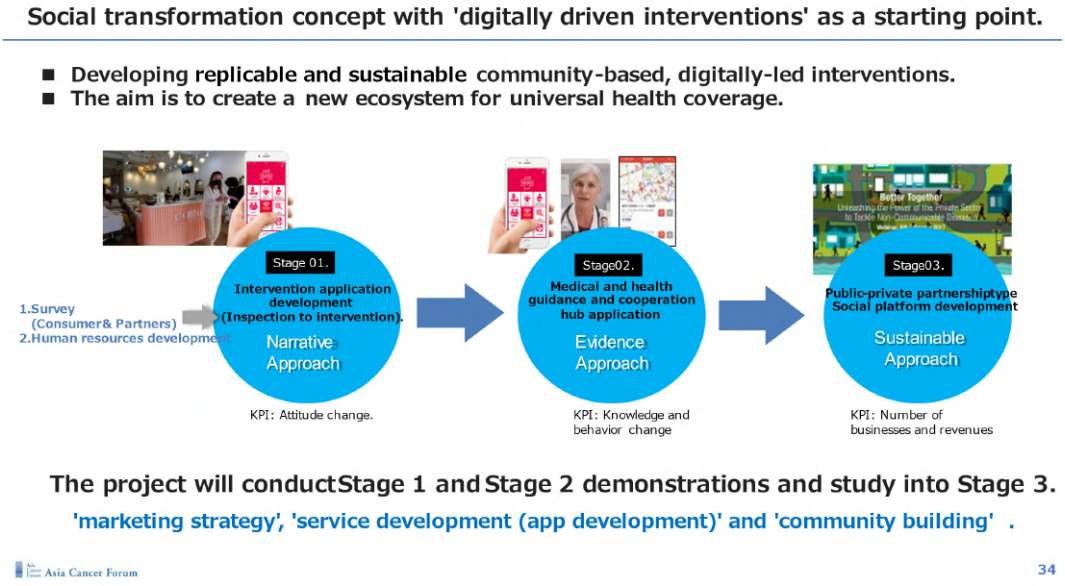


It is anticipated that the digitally-driven interventions that are scheduled to be implemented through the BEAUTY and Health Project will help to catalyze social transformation, and create social and economic value from a medical starting point. One of the rationales behind the project is that in the future tackling cancer will require a significant shift in the way we all live and work, and can only be achieved through an “all-society” approach, systematically combing the power and reach of all sectors.

The Partnering Initiative (TPI), the Union for International Cancer Control (UICC) and Bupa have worked together to co-create a partnering guidebook, *Better Together*, designed particularly for non-profit organizations seeking to partner with companies against NCDs. The guidebook sets out how to bridge the divide between societal sectors, and to engage with business and create effective partnerships to address the causes of NCDs. The Asia Cancer Forum is currently working on a Japanese translation of this publication, which it is hoped will help to share insights and best practices from various countries.

In terms of sustainability, it is hoped that the BEAUTY and Health Project will help to develop replicable and sustainable community-based, digitally-led interventions, leading to the creation of a new ecosystem that supports UHC (Figure 4).

Fig. 4 Anticipated stages of development of digitally-led interventions



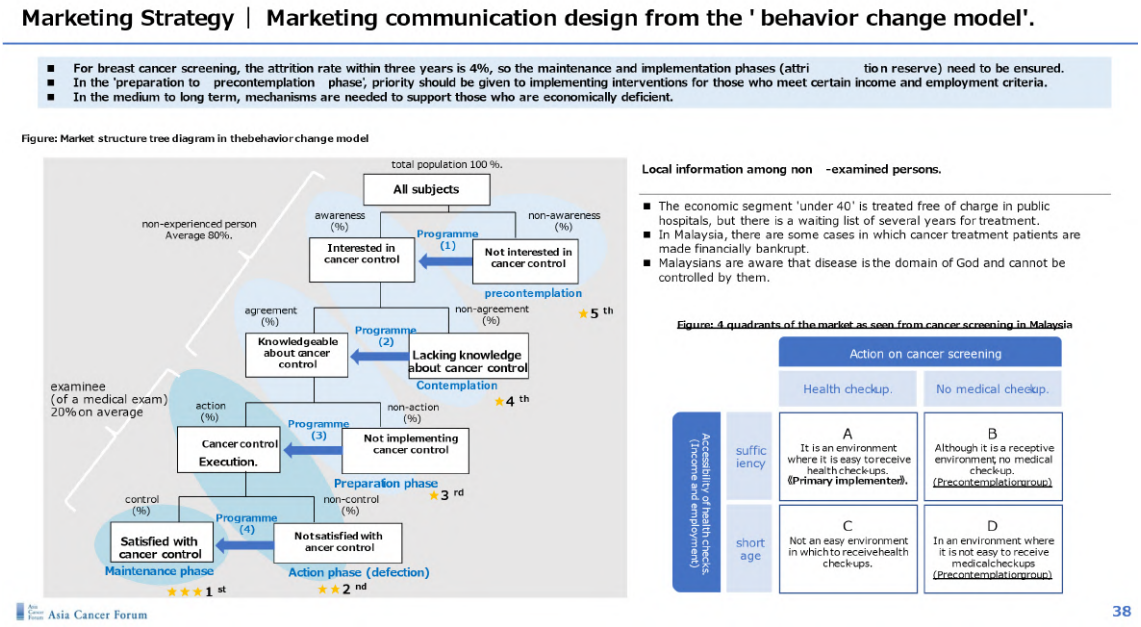
(7) Specifics of project implementation

In terms of the specifics of project implementation and some of the end targets that are envisaged, one goal is to boost cancer screening rates in Malaysia for common cancers, which currently stands at around 20%. As shown in Figure 5 below, cancer screening behavior of the Malaysian population generally falls into one of four quadrants. The aim of UHC is to cover people in all four quadrants. However, due to limited resources, it is important to develop a master plan to achieve the target and prioritize action plans in each quadrant.

Although people in Group A have ready access to cancer screening, even in this group it is important to ensure that attrition rates do not increase. People who fall into Group B have the greatest potential for boosting the screening rate in Malaysia, as they are in a receptive environment.

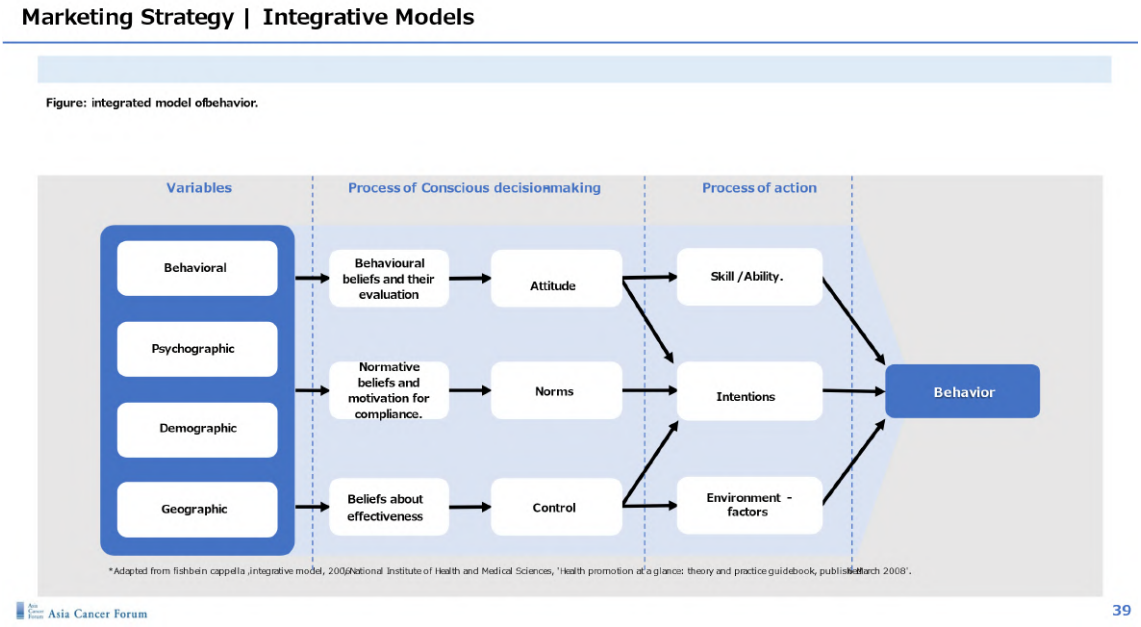
However, the currently reality is that Groups C and D combined account for 80% of the Malaysian population, so other support mechanisms are also needed, including the project's aim of implementing digital interventions through beauty salons.

Fig. 5 Marketing communication design based on the “behavior change model”



In designing an intervention support program therefore, individualized design tailored to the target is required. It is important to construct an intervention support program with high reproducibility by segmenting the targets at each stage of behavioral change using external variables and testing hypotheses on the decision-making process and the process of behavior change (Fig. 6)

Fig. 6 Integrated model of behavior



In preparation for the project the development materials are classified into three literacy levels based on the outcomes of a government health literacy survey. These literacy levels are defined as “limited,” “sufficient,” and “excellent.” The NCSM has also developed teaching and awareness materials that match these three levels of literacy in a total of four languages (Malay, Chinese, Tamil, English). It will be therefore important to explore the “level of interest” (interested/uninterested) within each group, in addition to their level of literacy. By conducting analysis of 24 attribute types and understanding their conditions and needs, it may be possible to formulate an intervention concept that is individualized and optimized according to each phase and create a single, all-encompassing mechanism.

(8) Digital specifics – What will the app do and how will it be implemented?

The app to be utilized for the project is called BEAUTY. It is anticipated that the app will be installed using beauty salons and barber shops as touchpoints. In addition to attribute information, information on other items such as awareness, knowledge, behavior, location and values will also be collected by the BEAUTY app as registered information.

The information registered on the BEAUTY app means that health levels can be monitored using the dashboard My Page on BEAUTY. The level of a subject’s interest can therefore be predicted from the personal information acquired, and a personalized program is developed accordingly within the app.

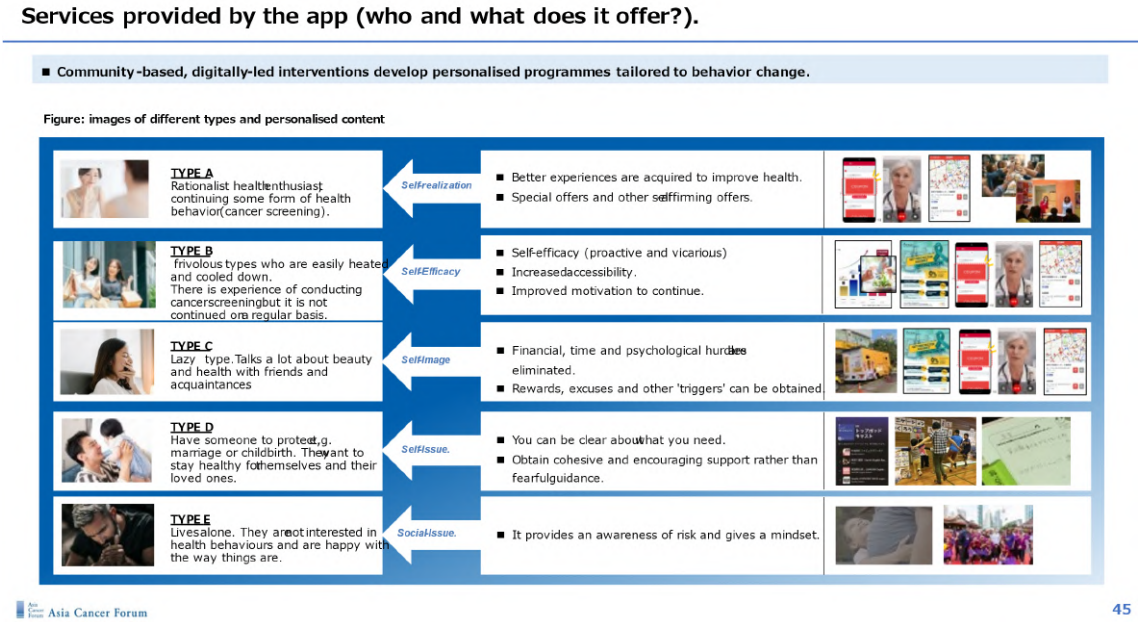
App functions can be built up in stages, giving consideration to the segments that need to be implemented.

The Japan project team is currently discussing the possibility of adding a points system to the app, as well as implementing a program that promotes circulation from urban to rural areas. It is very important to aim to realize a sustainable mechanism that will continue to revolve around the relationship with providers of content provision support. Collaboration with corporate health management practices will also be encouraged. In the initial

In the initial stages the aim is to use as narrow and precise a focus as possible, out of a desire to ensure adherence and continued use of the app and its features. Coupons and other incentives could be provided to enhance uptake of the app.

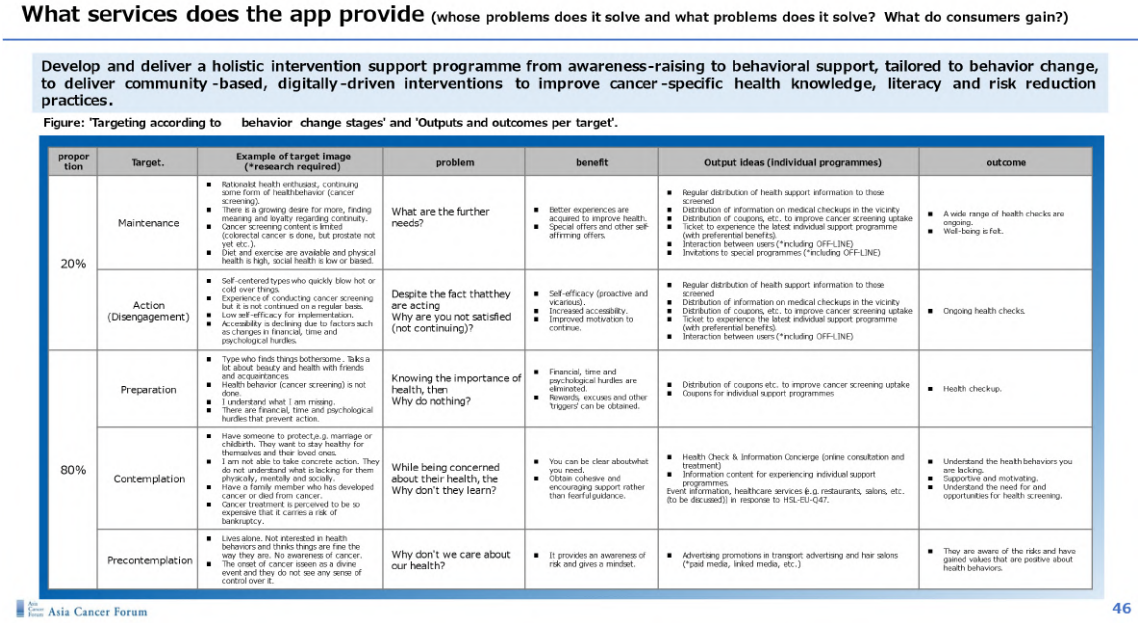
The app will aim to respond to and appeal to various types of people by providing personalized content for everyone from rationalist health enthusiasts, to people who seek to maintain good health for the sake of their children, etc. (Fig. 7)

Fig. 7 Anticipated target app user types



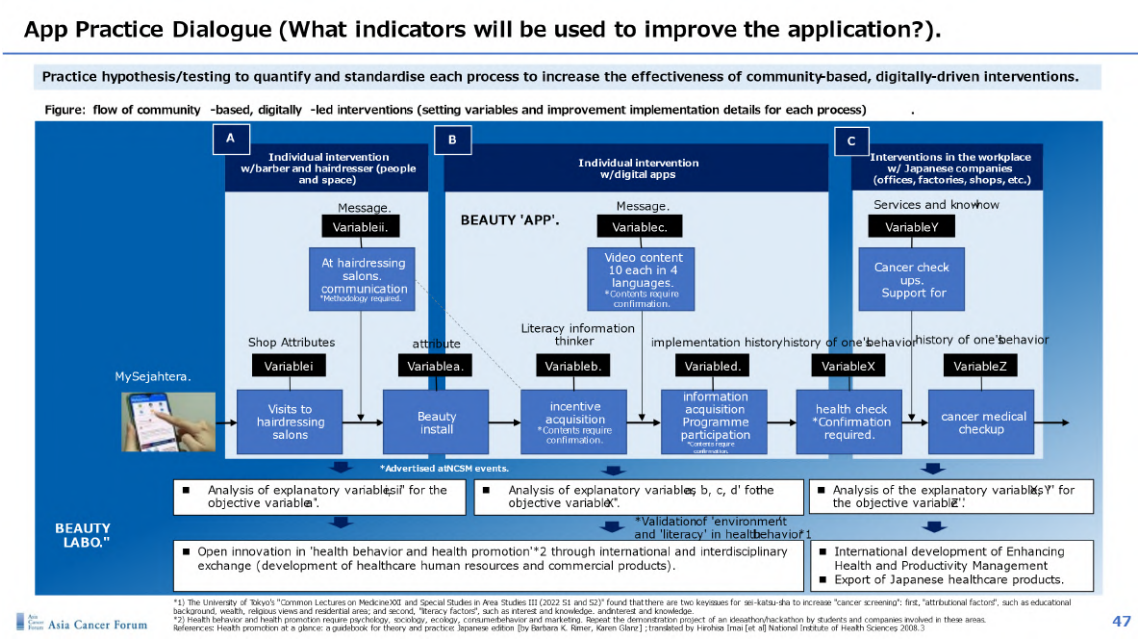
In terms of the services the app will provide and what and shoe problems it may be able to solve, the aim is to develop and deliver a holistic intervention support program from awareness-raising to behavioral support, tailored to behavioral change, to deliver community-based, digitally-driven interventions to improve cancer-specific health knowledge, literacy and risk reduction practices. The figure below shows a detailed image of the type of problems the app could solve, with anticipated benefits and output ideas.

Fig. 8 App services, problems responded to and potential outcomes



Once in operation the app will need to be consistently updated and improved. Accordingly, it will be necessary to formulate hypotheses and implement testing to quantify and standardize each process to increase the effectiveness of community-based, digitally-driven interventions. The figure below illustrates the indicators and variables that are planned to be used to assess and improve the app functions.

Fig. 9 Flow of community-based, digitally-led interventions



The final aspect of implementation will be to address the task of creating a sustainable system. The project team is in discussions with the NCSM to implement ecosystems and upscale activities to realize a self-sustaining ecosystem. As with all international joint projects, two-way conversations and searches for answers are of critical importance. Mutual trust and good intentions are essential in order to overcome any cultural or habitual differences.

(9) Next steps and outlook for BEAUTY

For a beautiful future and social implementation of cancer care that leaves no one behind, an urgent challenge is to engage in branding of the BEAUTY (Bringing Education and Understanding To You) concept and related mechanisms and functions as a digitally-led narrative-based intervention.

Beauty is both personal and universal, and the BEAUTY and Health Project has the ability to win the hearts and minds of people and change their behavior for the better. However, the key point of this project going forward is to realize the fusion of digital and human interactions.

This project will acquire information about people that originates in the relationships that people have with their hairdressers/barbers in their daily lives as touchpoints. Although digitally driven this is fundamentally a human-centered approach.

When approached about their hopes for the project, hairdressers in Malaysia responded positively, noting that although the topic of cancer may be difficult to bring up in the context of a beauty salon or barber shop, it is the hairdressers and barbers themselves who can adjust how they approach individuals to find the best time to broach subjects and in so doing personalize advice and information for each and every individual.

The project team will continue its efforts to reach out to more than one million Malaysians by promoting cancer prevention and early detection through health education and literacy.

Efforts and outcomes will continue to be monitored, analyzed and adjusted, and the Asia Cancer Forum and National Cancer Society Malaysia will report on progress regularly.