

TWELVE YEARS OF KWF (DUTCH CANCER SOCIETY) FUNDED HEAD AND NECK CANCER CARE AND RESEARCH IN INDONESIA

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In 2004, the World Health Organization acknowledged cancer as a worldwide problem. Due to the ageing population, it will become the biggest health care challenge for the future; especially in developing countries not prepared for this burden.

Since 1999, the Department of Head and Neck Oncology and Surgery at the Netherlands Cancer Institute and the Department of Pathology at the VU Medical Centre in Amsterdam have been involved in a KWF (Dutch Cancer Society) sponsored collaboration programme with the Gadjah Mada University in Yogyakarta, Indonesia. For the first five years, specialists from Indonesia were trained in Amsterdam followed by continuing on-site education by Dutch specialists visiting Indonesia. We also created new facilities for laboratory diagnosis and patient treatment (the Tulip Clinic) with funding from KWF and EU Asia-Link. Although the initial aim of this project was to build on the Department of Head and Neck Surgery and Oncology at the Dr Sardjito University Hospital according to the “teach the teacher” principle, it became clear after a few years of exchange programmes that this goal had to be adjusted. Basic requirements like international standard pathology, radiology and radiotherapy and also dedicated training programmes on head and neck surgery and oncology were not sufficient to build on such a high standard goal.

In 2005, a national training programme was organized in collaboration with a dedicated overseas faculty and Indonesian doctors, supported by all the major university hospitals in Indonesia, to create a new generation of head and neck surgeons used to working according to international standards.

One of the most important basic problems we came across was the lack of data management making it impossible to evaluate medical care and treatment results and provide doctors with feedback. The lack of accurate diagnostic and post-treatment data made it impossible to gain insights into the current problems in cancer care. Step by step we started to build on the infrastructure. Due to the many problems we discovered, it became clear we had to focus on one tumor type. Since

nasopharyngeal cancer (NPC) is the most common head and neck cancer and ranks fourth of all tumors in men in Indonesia the choice was self-evident.

Diagnostic and treatment protocols were developed and a multidisciplinary team was created to treat these patients according to internationally accepted guidelines and to build on a “blue print” for the treatment of this tumor type. These blueprints could be modified and extended to optimize the treatment of other tumor types in the future.

The protocols and treatment results can now be archived and monitored by using an online data-management system, which was developed in collaboration with the Department of Data Management at the Netherlands Cancer Institute in Amsterdam and which is also accessible from the Netherlands.

Using this data system, a recent evaluation of the treatment results of primary NPC showed that only 29% of patients had a complete response directly after treatment with a median overall survival of 21 months after diagnosis. Thirteen per cent of patients waiting for radiotherapy had already died of disease progression before the start of the radiotherapy. Twenty-nine per cent of patients died before a treatment response could be assessed. The main reasons for these poor treatment results are the long waiting times before the start of radiotherapy, the overall radiotherapy treatment time, the advanced stage of disease at presentation and the private costs of treatment for each patient due to the lack of proper insurance. The long waiting times are caused by a shortage of capacity in radiotherapy facilities.

In 2008, 18 linear accelerators and 17 Cobalt-60 teletherapy devices were available in Indonesia serving a population of 229 million. A substantial number of these devices were out of order on a regular basis.

The easiest way of addressing the current problems in Indonesia would be to establish sufficient radiotherapy facilities with well-trained personnel, however this will take decades. In the meantime, our goal is to work on early-stage cancer detection and to ensure that patients who are treated can have effective treatment and develop alternatives to improve cancer

care with the facilities currently available.

Projects and future plans

In the near future we will publish our results on the current pitfalls of cancer care in Indonesia with data on NPC patients. These results will be the first ever published on treatment outcomes of NPC in Indonesia. Most papers, addressing cancer-related problems in developing countries, highlight the increasing incidence, the problems of public, medical and political awareness and the lack of treatment facilities. It is certain that our results will have a more important political rather than scientific message but this will hopefully open the eyes of developing countries and the non-governmental agencies helping them.

We will continue collecting local Indonesian “real-life” data and by using this data we will organize customized training programmes in the hospitals and for general practitioners (GPs) in the front line. Many GPs are not aware of the frequency of NPC in their region and lack knowledge about symptoms and risk factors. With the education of GPs and Indonesian society, we aim for earlier detection and referral of NPC, better treatment outcomes and improved overall prognosis.

Alternative treatment modalities

The high rate of residual and recurrent NPC and the lack of radiotherapy facilities stresses the need for alternative treatment modalities. For seven years we have investigated the role of photodynamic therapy (PDT) for residual and recurrent NPC. PDT is a non-invasive treatment modality and facilitates tumor destruction by the combination of a photosensitizer and light. Besides good treatment response, PDT is inexpensive, has a short waiting time and the procedure takes less than 20 minutes and can be performed in the outpatient clinic. The preliminary results are promising. Future research projects are based on this therapy.

Besides this treatment we investigated the possibility of using Epstein-Barr virus (EBV) in the detection and treatment of NPC. NPC is causally linked to EBV, which makes the tumor an ideal subject for research projects. This has resulted in an understanding of the role of EBV in NPC and has allowed the development of early detection tests and alternative treatment options for Indonesian NPC patients, which are currently being tested in the field. Because virtually all NPC tumor cells carry EBV, this virus is a potential target for therapy. In the tumor cells EBV hides in a latent state and expresses only a few non-immunogenic viral proteins essential for EBV maintenance and contributing to tumor growth. We developed a cytolytic virus activation (CLVA) therapy for NPC treatment, reactivating latent EBV by epigenetic modulation, triggering immune

recognition and inducing susceptibility to antiviral therapy. The CLVA treatment was optimized and validated in NPC cell lines and subsequently tested in three Dutch patients with NPC, refractory to conventional treatment. This new treatment approach can be used to overcome the waiting times before radiotherapy or as a treatment for patients who are beyond cure due to metastasized disease.

Our main initiative in Yogyakarta for the coming years is to build an internationally supported cancer training centre. By introducing an international standard of care supported by a committed overseas faculty, Indonesian doctors can be trained according to western standards. Fellowships abroad as part of these training programmes, can only be effective in the long-term if teaching can be continued in Indonesia supervised by the overseas faculty. To achieve this training centres with international standards are required. Another advantage of building such centres is to create the possibility for high-income Indonesian people to have adequate medical care close to their family and friends instead of seeking care in Singapore or other countries. The money raised by this initiative can be invested in medical systems and treatment facilities in Indonesia but can also help the less privileged to get access to adequate cancer care as well (Robin Hood principle). The Minister of Health, the Medical Faculty and the University Hospital in Yogyakarta support this initiative and investors from overseas have already expressed their interest in such an initiative that could bring international standards to cancer care in Indonesia. ●

About the Dutch Cancer Society

Since 1997, the Dutch Cancer

everyone deserves a tomorrow



Society has been working hard to successfully improve the situation of patients with cancer in developing countries through its Development Cooperation Programme. The programme focuses on the collaboration between institutions in Indonesia and the Netherlands. This cooperation offers research opportunities that contribute to the mission of the Dutch Cancer Society in the Netherlands by providing new data for the Dutch setting and simultaneously improving the oncological care of patients and scientific research in Indonesia.

From 2013 onwards the Dutch Cancer Society will continue to contribute to global cancer control but in a different way. In order to make impact on the global cancer burden we believe in the concerted action of cancer societies. Therefore the Dutch Cancer Society will make a three year investment in the following UICC programmes: the Cervical Cancer Initiative and the Global Initiative for Cancer Registries. Fellowships are also an essential part of both programmes.

<http://dcs.kwfkankerbestrijding.nl>