

Tackling cancer the Tunisian way

→ Jim Boumelha

Farhat Ben Ayed played a key role in building Tunisia's cancer services, armed with little more than a solid education, a sense of duty and a remarkable talent for motivating others. Fighting cancer, he believes, is a question of citizenship and solidarity, and limited resources cannot be allowed to stand in the way.

Rising life expectancy, swift urbanisation and major changes in dietary habits all preface an inexorable rise in cancer. Tunisia fits this description. With 10,000 new cases a year, this small country is on a rising cancer curve. With the limited resources of a country in transition, it is about to cross its Rubicon.

Unlike many countries moulded by similar historical events (the French occupation ended 50 years ago), Tunisia has no army to speak of, investing its human capital in education and health. Tunisia's health budget tops 8% of national spending.

This is perhaps one reason why Professor Farhat Ben Ayed, the father of Tunisian oncology, is in an almost permanent state of reflection on the meaning of the fight against cancer, in particular with the cost "of what has already been done and what we have failed to accomplish". It is also a reason why equality of treatment has become almost an obsession. His commitment to cancer patients is a commitment to people's rights. "The fight against cancer

for me is not just a question of specialists, but most crucially an issue of citizenship."

In identifying risks and setting out strategies to improve prevention and early detection, to develop new therapies and to improve social rehabilitation, Ben Ayed is careful not to follow blindly the example of Europe. "We have different priorities. Our top priority is the fight to reduce tobacco consumption because lung cancer is the number one killer in our country. It cannot be breast cancer detection, where we are hampered by the fact that it is most prevalent among the under 35s, making it difficult to screen. With our foreign friends we discuss continuously what kind of projects we need to advance, what can or can't be achieved and, most importantly, what can we do to affect the maximum of people."

With 25% of cancer patients coming forward at such a late stage that curative treatment is no longer possible, it has been necessary to develop psychosocial support for individuals and families living with cancer. In the Tunisian context, oncologists have also to grapple with the



notion that cancer is a punishment. The first and most crucial action has been to focus on demystifying cancer which remains a taboo subject. Tunisian families live in such a fear of the disease that they cannot bring themselves to call it by its name.

“We are struggling to convince families that cancer is just like any other disease. In the pres-

ent state of thinking, it does not just affect the individual, but has an impact on the family as a whole. The whole family is weakened; their social status goes down, acute depression follows.”

Patients are developing higher expectations, both in terms of which cancers can be cured and what happens to patients when a cure is not possible. Palliative care and the concept of a hospital without pain have become the norm. Thanks to a monopoly on importation of drugs, the state-owned Pharmacie Centrale makes most drugs, including all types of opiates, widely available, putting Tunisia ahead of many other Arab countries in its ability to deliver pain relief.

Although Pharmacie Centrale imports most of the newer cancer drugs, Ben Ayed stresses that much of the progress, in particular in paediatric oncology, has been achieved by making better use of old drugs. The top priority must remain the overall interest of all patients and not just a privileged few, he says. Tunisia has not the means to gamble precious resources on a treatment that can only be used for 8% of patients.

The strong arm of the state makes a difference for both drugs and infrastructure – most hospitals are now equipped with scanners and there are six MRI machines in Tunis alone – but there is an acute need to further develop the national cancer plan, so that it does not remain the sole property of the cancer specialist. Ben Ayed argues that the involvement of citizens is a major missing component.

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Farhat Ben Ayed talking to patients at the Eddar Hospice in Tunis

Unlike oil-rich countries in the Arab world, Tunisia has no petrodollar reserves. Pioneers like Ben Ayed organise the fight against cancer with few resources, armed with a solid education, a sense of duty and exceptional organisational wizardry in the art of motivating others. Partly as a result, Tunisian oncology punches far above its weight.

Ben Ayed learned two things from his childhood – he assimilated from his home island of Djerba the art of being a hard taskmaster and, from his parents, a sense of giving without expecting anything in return.

He set out to study philosophy but converted to medicine once he saw his older brother in action – Si Hassouna was to become the first Tunisian nephrologist. Ben Ayed enrolled at the medical school in Montpellier, France, and conducted his postgraduate diploma at Tunis and the Gustave-Roussy Institute, in Villejuif, France.

Ben Ayed came home with a mission – to help build the foundation of medical oncology in Tunisia. He worked to strengthen the first and second pillars of this work, cooperation with the outside world and the Tunisian Cancer Institute (now called Salah Azaiez). The third pillar, the

creation of an association to fight cancer, is where he has concentrated his efforts for the last 20 years.

Over two millennia, Tunisia has been invaded by Vandals, Phoenicians, Greeks, Romans and Arabs. In modern times, it became a province of the Ottoman Empire and later a French colony. It is not surprising to find a tradition of cooperating with others profoundly ingrained in the country's psyche and within the scientific community. The French not only left a substantial legacy, but continued to play a major role in training Tunisian oncologists and helping the country develop its infrastructure.

Charles Nicolle, the first doctor to win the Nobel Prize in Medicine while working on African soil (he discovered the transmission agent for typhus), conducted his research from the Pasteur Institute in Tunis.

French oncologists gave the impetus in the late 1960s to creating what was to become the Salah Azaiez Institute, the nerve centre of Tunisian oncology and the first cancer institute in the Arab world.

Ben Ayed shows great respect for the personal commitment of French colleagues. "To be honest it was a generous cooperation. They gave so much and never asked anything in return."

His studies in France arose from a visit by a French team to Tunis during which he met Jean Louis Amiel, a leading oncologist at the Gustave-Roussy Institute, the beginning of a friendship that would last until Amiel died in 1985. "We went on to build an exceptional network of friends, people with an exceptional knowledge. This was the first step for us in building our knowledge of clinical oncology and understanding the founding principles of biological oncology. From there on, there was no going back. I was hooked into medical oncology.

"Many outstanding personalities like Professor Amiel became icons. He often travelled to Tunis as a friend not just as a colleague. And even today, after his death, when confronted with a thorny problem we often try to imagine: what would Professor Amiel do in such a case?"

The mix of professional and friendship ties meant that it was not difficult to involve colleagues from institutes and hospitals all over

France – Marseilles, Rouen, Lyon, Gustave Roussy Institute, St Cloud. A simple phone call was enough to convince them to make the trip. The multidisciplinary of the Tunisian cancer institute was in large part thanks to this input.

Other countries became involved. The Italians helping to set up screening for cervical cancer and short courses for doctors and interns.

Later, the training of trainers was taken up by the French national anti-cancer league with the help of the UICC. A French NGO, Douleur sans frontières, set up training to show general practitioners how to treat pain. International collaboration is still important. A soon-to-be-published report on the epidemiology of cancer of the larynx organised by the International Agency for Research on Cancer (IARC) brought together researchers from Tunisia, Indonesia, Canada, China and France. Tunisia is also involved in a number of international phase II and III research projects.

Tunisian oncologists also recognise the need to build horizontal links with colleagues from the rest of the Arab world and the African continent. Ben Ayed has been building steps towards lasting cooperation between oncologists from the Maghreb (“the West”) – made up of Morocco, Algeria and Tunisia.

“The Maghreb is my top priority. We all received the same French training, which makes it easy for us to work together and communicate. So it’s not difficult to knit a web united around common options and joint work.

“Every year there are 70,000 new cases of cancer – 30,000 in each of Morocco and Algeria and 10,000 in Tunisia. We are currently discussing whether all these new cases are receiving an adequate and correct treatment. It would be all too easy to find excuses because of our inadequate resources. But this should not prevent us from researching, for example, the psychosocial context – how to deal with the

quality of life in Tunisia and the rest of the Mediterranean region.”

Ben Ayed is less optimistic about links with the rest of the Arab world. He argues that the Arab League has the necessary structures to lead the fight against cancer in the region, but says that this is inhibited by rivalries between countries.

Tunisia would like to do more in the way of training for doctors from sub-Saharan Africa. Lack of international recognition for Tunisian diplomas means that there is little incentive for African doctors to do their training here. However, strong links have been built with French-speaking countries in West Africa.

None of this cooperation would have taken shape without the Salah Azaiez Institute as the engine driving the fight against cancer in Tunisia. Since its inception in 1969, the Institute has based its structures, development and day-to-day practices on the Gustave-Roussy Institute, including administration, care and training.

However, the Tunisian approach to cancer treatment and care has evolved from local realities. “Our starting point was to cure every case. We realised very quickly that we could not. This is one reason why developing palliative care became a prime dimension of our work. It is through training specialists in the treatment of pain and in palliative care that we managed to open the door for the training of paediatric oncologists. It has also led to the development of psychosocial support for individuals and families living with cancer.”

The Institute has revolutionised the teaching of cancer at the Tunisian medical faculty. For example, paediatric oncology was not recognised as a specialty at the faculty until it was practiced at the Institute. Today, Tunisian children’s hospitals all handle childhood cancers. The Institute also encouraged the publication of high-quality research reports by Tunisian teams

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on child lymphomas, breast cancers and other topics, raising their international profile.

The Institute has influenced other regions of Tunisia – Sfax and Sousse are also developing as major cancer treatment centres. Multidisciplinary treatment, palliative care, psychosocial themes, and research have become central pillars in the fight against breast, colorectal and lung cancer.

Many doctors are still sent abroad to learn new approaches to treatment and care. A few stay away, lured by better wages and prestige. However, most return with a renewed allegiance to their home country and find immense satisfaction in what they are doing. “When 80% of children are cured of cancer, isn’t it great to see some of them growing up and becoming doctors or engineers,” notes Ben Ayed with a smile.

He believes that an effective fight against cancer rests on a partnership between the public, the private and civic society. “Every person has a role to play. Cancer is a question of solidarity. Everybody should join the fight.”

After years of developing medical approaches to cancer treatment, Ben Ayed was spurred to greater action by seeing patients in distress. In 1987, with friends and co-thinkers, he created the Tunisian Association for the Fight against Cancer (ATLCC), and in 2000, the Association for the Promotion of Pain and Palliative Care.

In the hands of Ben Ayed, the ATLCC has grown into a humanitarian and scientific association with a public service brief, that also promotes teaching and prevention.

Thirty percent of cancers in Tunisia are linked to the environment and 40% to tobacco, especially cancers of the lungs, throat and bladder. The campaign against tobacco has become the top priority for the association. This ranges from efforts to convince farmers to replace tobacco cultivation with other crops, to lively teach-in

sessions in partnership with the train company SNCFT on one of their busiest commuter lines. Indeed, ‘smokeless’ trains have become a renowned feature of World Anti-tobacco Day, attracting positive coverage on Tunisian press and television (although they revert to being ‘smoking’ trains the next day).

Ben Ayed is committed to change in a country where virtually half of men smoke. (A World Health Survey in 2003, showed that 49.5% of men over the age of 18 smoke, while only 2.4% of women over the age of 18 do so.) He said: “I admire the Canadians and Irish for their willingness to confront the tobacco lobby and take effective action. In Tunisia we have adequate legislation, but nobody takes any notice. In a recent study we found that 95% of people are well aware of the risks. Our aim is not just to inform but to change behaviours.”

He believes in the value of engaging children at school about the risks during special national and regional anti-tobacco days. When children go home they take with them the knowledge and arguments they have heard – a powerful means to debunk myths with parents and family.

Education, training and information are the bedrock of the ATLCC prevention strategy. Special programmes, such as palpation techniques for breast examinations, are aimed at the general practitioner (GP), who is seen as the first line of defence. Ben Ayed believes that the GP must also be an educator and a communicator.

National training days, conferences and seminars are other useful ways to reach specialists. A two-day international seminar was organised in Tunisia by Ben Ayed and Franco Cavalli from Bellinzona, Switzerland, with the European School of Oncology in December 2005.

The ATLCC is often at its most creative

when raising money. It raised funds to buy the first mammography machine for the Cancer Institute and teamed up with a chemical company to buy another for Gabès hospital in the south.

The success of the association shamed the authorities into action. Treatment centres opened in Sousse and in Sfax. The Government also released land to the association to build Eddar hospice. It was built with hard work and determination – a dinar here and a lorry-load of bricks there – with Ben Ayed as motivator, campaigner and executive. He asked students at the school of architecture to lend a hand with the design. He begged students elsewhere to sell postcards for a year to furnish it.

Since its launch in 1993, the hospice has lodged more than 1,000 cancer patients, most of whom needed somewhere to stay during treatment in Tunis. Thousands of other patients have received financial help. Ben Ayed says that the tremendous wave of solidarity around building the hospice grew stronger after it opened. “Scores of volunteers are involved day in, day out, in a loose support network. Some prepare the food, others just give moral support.”

Now Ben Ayed has set his sight on building, with the help of the Ligue française contre le cancer and the UICC, an information centre to be used by the public and the media, as well as by students and health professionals.

Leading oncologists do not often vacate their labs to negotiate deals with outside organisations. One of the most imaginative was with the national train company. Backed by the cancer institute, the association agreed to screen the rail company’s female staff for cervical cancer, in exchange for SNCFT agreeing to transport cancer patients to and from treatment centres free of charge.

Another idea was to recycle printer cartridges, which raised awareness about environmental issues and paid for a mammography machine.

Ben Ayed says: “With limited resources, the only option open was to innovate and develop activities commensurate with what is achievable. In Tunisia everything is a priority, but this should not be an excuse for doing nothing. We should be



Ben Ayed with Henda Raïs, the first doctor in Tunisia to be trained as a specialist for pain and palliative care in cancer

able to take care of our needs and better manage our expenditure.”

The association has also focused on developing palliative care, becoming the local chapter of the International Association for the Study of Pain.

It has found time to address ethical issues, bringing together a philosopher, a jurist, a nurse and a sociologist to discuss clinical research and trials. Ben Ayed brought in his own expertise as a member of the French and Francophone Society of Medical Ethics at University Paris V.

He concludes that value judgements are not the same everywhere. “Ethics concerns personal behaviour but it is also a reflection of society. However, we found in the end no difference between different religions in their stand on ethical questions.”

Ben Ayed is renowned for saying little and saying it quietly. He abhors loud plaudits. He grapples with philosophical concepts and aspects of humanity beyond what can be recorded on charts and medical records. Without raising his voice, he sums up his quest: “I want Tunisians not to be afraid of cancer anymore.”