

How cancer hit the Romanian political agenda

➔ Jim Boumelha

Romania's forgotten cancer patients erupted onto the public scene when they staged a demonstration outside the Ministry of Health in May. Things will never be the same again...

When cancer is taboo, patients suffer – not least because health systems can get away with ignoring their needs. This has long been the case in Romania, where spending on cancer is reported to account for around 0.3% of the health budget, compared to figures like 4.8% in Germany, 4.7% in Sweden, and 3.9% in the Netherlands and the UK. But things are finally changing.

After years of battling to get cancer onto the political agenda, a federation of patient and advocacy groups hit the headlines in May – and not just in Romania – when a small but determined group of cancer patients besieged the Ministry of Health as their representatives went inside with a list of demands:

- Give immediate access to treatment for all cancer patients
- End the bureaucratic obstacles patients face in getting the go-ahead for their treatment, and provide written justification when any treatment is refused
- Introduce transparency into the public health regulations
- Set up a cancer registry to recognised standards
- Allow free access to supportive treatments and breast prostheses
- Give all patients access to care by specialists – including trained medical oncologists

- Prepare a national cancer plan covering everything from prevention to rehabilitation

After two hours the patients chalked up their first victory. They were given two seats on a revamped Oncology Commission – a body set up by the government that brings together patients, oncologists, government officials and health insurers. Marlene Farcas is director of the Societatea Romana de Cancer, one of the advocacy groups supporting the protest. She believes this step marks a real change. “This commission is not just a talking shop. Its brief ranges from access to drugs to re-equipment of hospitals, training of oncologists and cancer registries.”

Florin Băcanu, an oncologist who has been newly elected onto the Commission, says the patients' protest was enormously important in helping to usher in a new era of democracy in decision-making – and not just in patient representation. “For the first time, oncologists were able to vote freely for their representatives without undue influence.” He is unhappy that hospital-based oncologists are over-represented, but says this is nothing compared to the old times when only professionals who were politically involved would get access to the decision-makers.

Members of the Oncology Commission have a huge task ahead of them. According to official estimates, out of the 400,000 patients diagnosed with cancer, only 76,000 are currently in treatment – a



Top: Corina Alexandru, president of the Asociația Oncologicărom in Constanta, talks to the demonstrators. Middle: Health Minister Eugen Nicolăescu comes out to talk to the press. Bottom: Cezar Irimia, vice-president of the Romanian Federation of Cancer Societies talks to a policeman whose mother is on the

demonstration. Alexandru and Irimia were among the five-strong delegation that met the Minister. Irimia was elected as one of the two patient reps onto the revamped Oncology Commission



reflection of the tiny proportion of the health budget spent on this disease. Every aspect of cancer treatment is in a grim state – access to drugs is poor, equipment is out of date and worn out, specialist training is limited to doctors in a handful of cancer centres, and a significant section of the poorest population has almost no access to free healthcare. Worse still, there are no systems in place for collecting and analysing the data necessary to get a grip on the situation.

The Commission has hit the ground running. Farcas is impressed at the way it has got down to business in its first two meetings, mapping out a strategy for improving cancer treatment, and she welcomes the spirit of cooperation among its members – including health officials and representatives of the national health insurance agency. “The plan in general is done,” she says. “They know what they have to do and the Ministry agrees to what they have to do. But it needs time to be organised.”

A QUESTION OF MONEY

Băcanu is more cautious, and reckons that all the plans on paper, however welcome, will only become meaningful when the government agrees to back them

with hard cash. He accepts, however, that early progress has been made on some important issues such as the setting up of cancer registries. “Having agreed that the cancer registry starts from the GP [general practitioner], it was not difficult for the ministry to agree to give every GP a computer so they can set up a database and transmit the results,” he says.

But many other core issues detailed in the protesters’ list of demands, such as access to drugs and the training of oncologists, are likely to prove harder nuts to crack.

Băcanu says that ambulatory patients, in particular, face major problems getting access to cancer drugs that have to be administered intravenously. The reason, he says, is that the list was not discussed by

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professional organisations such as the Society of Medical Oncologists, and that the new regulations were proposed by hospital-based oncologists who dominate the Commission, and are blind to the needs of patients who are treated in the community.

This bias, he says, is also reflected in the disparity between the budget available for hospitalised patients and the outpatients, which he passionately argues must now be addressed as a priority issue. “All these new drugs are approved by the commission of the health insurance system, but the financial support for this plan is very poor and only around 5% of the patients on the waiting list can actually have these new drugs. This is a big sadness for the oncologists. We want to treat all the patients. By what criteria can we choose this 5% from the waiting list?”

The training and status of oncologists have proved less controversial. The Commission has made a strong recommendation that not every surgeon has the right to operate on cancer, says Băcanu. Surgeons will not be allowed to operate if they have no specialist training or if their institution is not recognised as competent to manage cancer patients, and in some cases, such as breast cancer surgery, they must have a minimum annual case load.

Another key concern has been reversing a decision taken last year to withdraw the status of medical oncology as a specialty. This would mean that cancer patients will in future be treated by doctors who are trained only in internal medicine, with only five months training in oncology, in contrast to the five years of training that used to be required. Romanian oncologists took the issue to court, and won a ruling in their favour. Though the Ministry promised to abide by the ruling, it has not said when it will do so.



Taken as a whole, things are certainly moving in an encouraging direction. Băcanu argues, however, that cancer patients will only feel the impact if politicians show political will and harness the power of the media to change public attitudes towards cancer. Above all, the issue of how Romania will finance an adequate healthcare system needs

to be tackled head on in the public arena. He wants the chance to present to a mass audience the dilemma faced by oncologists when they cannot do much except put patients on a waiting list. “It is necessary to explain to civic society that there is an urgent need to increase taxes to fund the health care system,” he says, adding that the discussion needs also to look at other ways of funding healthcare. He is encouraged by moves in the media itself to address some of these issues, citing a new TV channel called ‘Good Life’, which gives extensive coverage, including debates, to health and healthcare issues.

Farcas does not deny that adequate resourcing will be necessary to pull cancer treatment up to European standards. But she believes the first crucial step was to make the voice of patients heard. And it has been heard, loud and clear.

“I don’t want to defend the Ministry,” she says “but I observe that they have, for example, made huge progress in communication with the population, and with the patients they have a very open strategic platform already. Today I can phone the Ministry and ask questions such as when and how will you sort things out, and they give me names and answers.” Anyone who has spent as many years as she has trying to get information and responses from the shadowy figures who used to run the health show in Romania will understand just what a step forward this is.

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