Award for journalist who exposed failings in Hungary's cancer services

Viktória Kun, Health Correspondent on the leading Hungarian national daily newspaper *Népszabadság*, is one of two winners* of this year's ACE (Awarding Cancer Enlightenment) Reporters' Award. Here we reprint an article in which she highlights flaws in the country's oncology services that are responsible for some of the worst outcome statistics in Europe.

"My patient was complaining about severe pain in the limbs and arm atrophy. We soon discovered that the continuous pain was caused by a cancer that had spread. The primary tumour had been found in the breast of this middle-aged woman four years ago. At this time it had not spread. She did not get any treatment after her surgery, therefore no efforts were made to prevent what could have been prevented at that time. Another, a young girl – scarcely 20 years old – was referred to me recently with continuous diarrhoea.

On examination we discovered a tumour of her colon, despite the fact that her uterus had been removed only one month previously because of a cancer."

These are just two stories one general practitioner has dealt with over the past few months. Along with the experience of his own wife, they illustrate the significant problems of cancer services in Hungary today.

"My wife was diagnosed with a breast and ovary tumour four years ago. At the time it was thought to be inoperable, and treatment with Taxol was recommended. She was referred to a gynaecologist whose first sentence was: 'You are welcome but there is no Taxol.' I used my contacts to get access to the necessary medicine; however, my wife did not tolerate the chemotherapy very well. It was thought that this was due to an allergy and therefore treatment was stopped immediately and another treatment prescribed. We tried everything. Subsequently, it was discovered that it was not an allergy, but the dose of the medicine was wrong. When my wife was in a very poor

---

* The other joint winner of the 2005 ACE Reporters Award is Ioanna Soufleri, Science Editor on the Greek national daily newspaper *To Vima*. One of her articles will be reprinted in the next issue of *Cancer World*

„Taxol, az nincs…”

Magyarországon ma a daganatos beteg gyógyulási esélyei rosszabbak, mint akár tőlünk pár száz kilométerre. De még az országon belül sem mindegy, ki és melyik intézetbe kerül. A szakorvosok epidemiológiai válságról beszélnek.

KUN J. VIKTÓRIA

– Karsorvadásra, erős végtagfájdalomra panaszkodott a betegem. Rövid időn belül kiderült, hogy daganatos betegség okozza a folyamatos fájdalmakat. De már nem is csak egy helyen. S mindez nem először. A középkorú hölgy mellében négy évvel ezelőtt már találtak daganatos elváltozást. Igaz, akkor még csak ott. Az operáció után semmilyen utókezelést nem kapott, így nem előzték meg az akkor még megelőzhetőt. Egy másik, alig húszéves fiatal lány a napokban keresett meg azzal, hogy folyamatosan hasmenése van. A vizsgálatok vastagbéldaganatot igazoltak nála, jóllehet egy hónappal korábban távolították el a méhét, ugyancsak rákdiagnózis miatt.

Ez csupán két történet annak a háziorvosnak az utóbbi néhány hónapjából, aki saját feleségével a mai onkológiai ellátás szinte minden alapvető gondját megtapasztalta.

– Emlő- és petefészek-daganatot diagnosztizáltak a feleségemnél, éppen négy éve. Azt mondták, operálni nem lehet, Taxol-kezelést írtak elő neki, s egy nőgyógyászhoz irányítottak, akinek az első mondata az volt: jöjjenek nyugodtan, de Taxol, az nincs. Amikor orvosi kapcsolataim révén eljutottam oda, hogy végül megkaptuk a megfelelő gyógyszert, a kemoterápián a feleségem rosszul lett. Rögtön kijelentették, hogy allergia, úgyhogy a terápiát félbehagyták, majd újabb és újabb készítményeket kapott. Csaknem a teljes kört „végigzongoráztuk”. Utólag fedezték föl, hogy nem allergiáról volt szó, hanem rosszul adagolták a készítményt. Amikor pedig már nagyon rossz állapotban volt a feleségem, és folyamatosan csapolásra jártunk, elvittem volt évfolyamtársamhoz, aki sebész. Ő úgy döntött: megműti a nejem. Így derült ki, kétéves procedúra után, hogy a tumor műthető. A feleségem most jól van, holott akkor csak hónapokat jósoltak neki.

Dank Magdolna | Kismarton Judit | Magyar Tamás

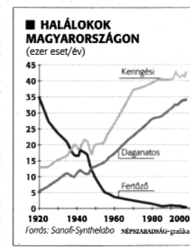
Ehhez hasonló esetek sorával találkoznak jogvédők, betegszervezetek képviselői vagy a szakemberek. Azaz, hogy nem a megfelelő helyre, s időben kerülnek a segítségre szorulók. Ma a betegek jelentős részét csak akkor látja az onkológus, amikor a daganat már áttétes.

– Petefészekműtéteket az ország szinte valamennyi kórházában végeznek, annak ellenére, hogy a beavatkozás szakmai feltétele a patológiai háttér, ráadásul elméletileg kizárólag onkológiai centrumokban engedélyezik az ilyen operációt – mondja dr. Ruzsa Ágnes, a Zala Megyei Kórház onkológiai osztályának vezetője. – Ma bármelyik kiskórház bátran elvégez daganateltávolítást, nemegyszer anélkül, hogy onkológus látná a beteget. Kiveszik a daganatot, lezárják a sebet, majd hazaengedik a gyógyultnak tekintett pácienst – mondja a doktornő, aki szerint alapkövetelmény lenne, hogy a rákbeteg utókezelésre, kemoterápiára kizárólag onkológiai osztályra, centrumba kerüljön. – Másik, szintén nem ritka gyakorlat, hogy „adjunk valamit” felkiáltással, a protokollokat, szakmai előírásokat figyelmen kívül hagyva, nem megfelelő dózisban és időintervallumban adnak valamilyen terápiát. A fontos az, hogy ott maradjon a beteg – állítja Ruzsa Ágnes.

Dr. Thurzó László, a szegedi onkoterápiás klinika vezetője országos felmérést készített a petefészek-daganatok kezeléséről. A vizsgálatok szerint az adott évben mintegy ezerkétszáz felismert és jelentett beteg közül mindössze négyszáznyolcvan kapott ezerhatszáz kemoterápiás kezelést. – A betegek alig harminc-harmincöt százaléka jutott el utókezelésre, azaz részesült szakszerű ellátásban. A többieknek nyoma veszett, elkallódtak a rendszerben. Ez az arány pedig még akkor is lesújtó, ha közöttük vannak idős betegek, akik nagyon rossz állapotban vannak, s emiatt maradnak ki a terápiából – állítja Thurzó László.

Dr. Magyar Tamás, a budapesti Péterfy Sándor utcai Kórház vezető onkológusa egyenesen azt mondja: jelenleg egy daganatos beteg sorsa attól függ, hogy ki észleli először a bajt. Egy rákbeteg minden olyan terápiát, kezelést megkaphat ugyanis, amit bárhol máshol a világon, a hiba elsősorban nem ebben van. – Egy éppen nagykorú lány került hozzánk, akinek kivettük a petefészkét. Műtét közben derült ki, hogy rosszindulatú daganata van, ráadásul annak is egy nagyon veszélyes típusa. A leleteit konzultációra még Amerikába is kiküldtük, s a vélemények összegzése alapján kapta a terápiát. Ma gyógyult. Ha mindez egy kiskórházban, bármilyen onkológiai háttér nélkül történik, nem él már a lány!

Magyar szerint az elérhető és szükséges diagnosztikai eszközöknek általában mindössze negyven százalékát használják ki egy-egy ráktípus pontos azonosításához. – A kismedencei daganatoknál például kötelező az MR-vizsgálat ahhoz, hogy pontosan tudjuk, mi a szükséges, leghatékonyabb terápia. Ez most mindössze az esetek felénél történik meg. Jóllehet így legalább ötven százalékkal javulhatnának a gyógyulás esélyei. Ilyen például a tumormarker-vizsgálat: a helyzetet egyértelműen mutatja az a tény, hogy míg ebből a vizsgálatból Magyarországon évente háromszázötvenezret végeznek, Ausztriában több mint kétmilliót – mondja dr. Magyar. – Ráadásul idehaza az orvosok egy része pillanatok alatt kimond egy végleges diagnózist, mármint hogy a beteg menthetetlen. – A leggyakrabban olyan esetekkel találkozunk, akikről vidéki kórházakban vagy más, esetleg kisebb intéz-



NÉPSZABADSÁG

Kun’s article, which originally appeared under the heading *No Taxol*, alerted the public to the fact that, as a cancer patient, your survival can depend on where you are treated – and that in turn can depend on who you know or how much ‘gratitude money’ you pay

condition and had continuous need for tapping of ascites, I took her to my classmate who is a surgeon. He decided to operate. This is how, after two years, they discovered that my wife’s tumour was operable. My wife is now feeling well, although at that time she had been told that she had only a matter of months to live.”

Lawyers, specialists and representatives of patient associations come across many similar cases of patients who are not referred to a specialist centre in a timely manner. In most cases today the oncologist only sees the patient when he or she already has advanced disease.

“Ovarian surgery is done in nearly all hospitals in the country despite the fact that in theory these types of intervention are only permitted in cancer centres with good pathological services,” says Dr Ágnes Ruzsa, head of the oncological department of the Zala County Hospital. “Today cancer surgery is carried out in nearly every small hospital in the country. Sometimes the patient is never referred to an oncologist. They just remove the tumour, they assume the patient is cured and send them home.” According to Dr Ruzsa, who believes it should be a fundamental requirement that subsequent chemotherapy should be done only in oncology departments or centres, another common practice is that they say, “We must give something,” so they give some chemotherapy, but in the wrong dose and without keeping to established protocols and prescriptions. “The important thing is to keep the patient.”

Dr László Thurzó, head of the oncology clinic of Szeged, has carried out a survey of the treatments of ovarian cancer. He found that, in the given year, only 480 patients out of 1,200 had been given chemotherapy. “Only 30–35% of the patients were referred to follow-up care and were therefore treated adequately. The others disappeared from the system. This result is damning even if we take into account that the

figures include a number of older people who were in poor physical condition and therefore were not eligible for treatment," says Dr Thurzó.

Furthermore Dr Tamás Magyar, the leading oncologist of Sándor Péterfy Street Hospital, states that cancer patients' outcomes depend on where the disease is diagnosed. In some centres cancer patients can receive state-of-the-art treatment like anywhere else in the world, so this is not the primary problem. "For example, we have just removed the ovary from an eighteen year old girl. It turned out that the ovary contained a very dangerous type of cancer. The results were sent to the US for consultation, and she received the most appropriate therapy. Today she has recovered. If this had happened in a small hospital without an oncology background, this girl would not be alive today."

According to Dr Magyar, only 40% of the available diagnostic instruments are used to diagnose cancer. "For instance, in the case of pelvic cancers, MRI scanning is obligatory in order to determine the most effective therapy. Nowadays, this happens in only 50% of cases, even though carrying out the scan significantly improves the chances of being cured. This is also the case with tumour marker examination. In one year only 350,000 examinations were done in Hungary, while in Austria more than 2 million examinations were undertaken," says Dr Magyar.

"Moreover in Hungary some doctors are all too quick to state that the patient is beyond hope. In most cases we see patients whom doctors in a county or smaller hospital have given up on, despite the fact that their tumour is operable and can be treated. The only option for these patients is to look for an informal route to getting back into treatment, by seeking contacts via friends and relatives. These are the ones who refuse just to sit back and wait to die."

Carelessness? Negligence? Lack of professional expertise? Fighting for patients or reputation? Experts say that all of these are to blame for the fact that 30–40% of patients do not get adequate treatment today.

According to Dr Magyar, it is inexplicable why AIDS patients must by law be referred to a specialist institute, while in the case of cancer patients there are no such requirements. Moreover, mistakes are rarely highlighted.

"The efficacy of a clinic, department or doctor is rarely monitored," says Magdolna Dank, head of the department of the Radiological and Oncology Clinic. "This means that clinics and doctors get away with prescribing incorrect doses and regimens of chemotherapy. It is not uncommon for departments that are not eligible to use chemotherapy to prescribe a completely different drug rather than refer patients to a specialist institute where he/she could get the appropriate treatment. Medicines have different prices, and the patients could be given different drugs. Most of the time a small hospital – usually for economic reasons – chooses an inappropriate treatment, but the insurance pays for this treatment anyway. There is a need to evaluate each clinic and department, to determine which cancer services they should be allowed to provide. Moves are already afoot to regulate this situation, and departments have been informed which treatments they are authorised to administer. However, so far this is not being enforced," says the specialist medical oncologist.

Clinics and doctors get away with prescribing incorrect doses and regimens of chemotherapy

According to Dr Dank, the absence of specialists is causing great problems. There is a lack of specialists in medical oncology, radiation oncology, radiology and pathology. Furthermore, it is very difficult to recruit doctors to work in oncology. Without new blood, the future of oncology is uncertain. It is widely agreed that a multidisciplinary approach is required to devel-

op the best treatment plans and that a team should consist of radiation oncologist, pathologist, medical oncologist, surgeon, and where possible a psychiatrist. However, this is very difficult to achieve in the absence of specialists.

Mr Szabolcs Ottó, the vice director of the National Oncology Institute, speaks of an epidemiological crisis, because Hungarian cancer statistics are so much worse than could be justified given the country's level of development and the age profile of its population. International data show cancer incidence at 50,000 per 10 million inhabitants, while in Hungary the figure is nearer 70,000.

Mr Ottó has been looking for answers to the question of why so many Hungarians get cancer and end up dying from their disease, and what can be done about it. Besides the most common reasons such as smoking, alcohol and poor nutritional habits, he thinks the organisation of Hungarian cancer services plays a role, as does one other important factor: the lack of an open and honest relationship between the doctor and the patient.

Statistics show that a patient who is treated in Hungary has a 10–15% lower chance (or for some types of cancer even worse) of surviving a cancer experience than those treated in western Europe. But even within the country there are differences.

According to the Hungarian Association Against Cancer, patients are sometimes told that their required treatment is either not available, or not covered by health insurance. "Every autumn and summer patients have to face the fact that the money to pay for cancer treatments has run out and therefore hospitals stop offering these treatments," says Mrs Vasváry, the leader of the Association.

Most of the supplies of cancer medicines are allocated to the National Oncology Institute, and the drugs are allocated on the recommendation of specialists. According to oncologists and insurance companies, it is not possible for a patient to be unable to get the necessary drug, but patients' experiences tell a different story. Sometimes the National Institute refuses a request from a county hospital. In this case, patients either have to wait two to three weeks or start the treatment with another, less effective medicine. Sometimes doctors stop therapy in the middle of the course of treatment because there is no more drug available.

You can come across cases like this, even though the primary duty of all oncology departments is to provide all the necessary medication, even if sometimes it means that they have to use the medication of somebody who has passed away.

Cancers are classified into four stages. In stage I nearly all patients are curable. In the second and third stage 30–50% of patients can be cured, depending on the type of cancer, and in the fourth stage almost nobody can be cured. In Hungary, nearly one quarter of the patients are diagnosed with stage IV disease.

"It is fundamental that patients with tumours will do anything to be cured," says Dr Magyar. "In my hospital it is not possible for the leader of the decision-making team, who has the power to decide where a patient is referred, to live off 'gratitude money' [bribery], because we have an oncological committee which decides on a random basis who is referred to which doctor. I have very little face-to-face contact with my patients, and in this way my decisions can be independent."

But generally the words of the doctor-lawyer Dr Judit Kismarton are true: it is definitely the 'gratitude money' and the economic situation that are to blame for the fact that most patients are referred too late to the appropriate institute. "The fact that in many hospitals the patient is not referred to an oncologist, but is simply operated 'in-house', even if the cancer has spread, without preliminary investigations or follow-up treatment, is because by referring the patient on, the hospital loses out on both the health insurance payment and the 'gratitude money'".

Last year, according to the cancer registry, 78,000 cancers were diagnosed in Hungary. If we could implement international standards we could improve our average survival figures by 10 years. In the past 25 years the number of people registered disabled because of cancer has doubled, despite the fact that the criteria for being registered disabled have been tightened.