



Patients pay a price for spending cuts

→ Anna Wagstaff

Austerity measures brought in to tackle the debt crisis are affecting frontline healthcare services in many countries, particularly in the complex, expensive field of oncology. *Cancer World* asked its readers to share their first-hand experiences.

Doctors are sounding the alarm about the price cancer patients are paying for dramatic cuts in public spending. In the countries hardest hit by Europe's debt crisis, services are hit from many directions at once: staffing cuts leave some operating theatres and linear accelerators idle, while patients flood into the public service because they can no longer afford private health insurance. Patients are also increasingly unable to get hold of drugs they need, as pharmaceutical companies withhold supplies due to unpaid bills – a problem

which may be exacerbated by a growing re-export trade in which drugs bought at a lower price negotiated by debt-stricken governments find their way onto international markets to be sold at a profit.

John Spiliotis, a director and chairman of first department of surgery, and president of the scientific council of the Metaxa Memorial cancer hospital in Piraeus, Athens, describes the situation as working in “wartime conditions”. His hospital has seen a 50% cut in its budget over the last three years, while admissions have increased by more than 30%. “If you compare

these two figures, the conclusion is maybe we have a crisis in the management of cancer patients,” he says.

Public sector employment rules that permit only one position to be replaced for every 10 that are lost are creating acute staff shortages that impact directly on patient care. At the Metaxa Memorial hospital two out of six operating theatres are now unused because there are too





in the battles between the Ministry of Health, pharmaceutical companies and pharmacists.

There are worries too that financial concerns are leading patients to delay visits to a doctor. "We have a problem that 15–20% of patients do not consult a physician. We compared results from 2007 to 2009, and it seems that we are seeing cancer patients at a more advanced stage than three years ago, though we do not have statistically significant data on this as yet." If true, this would mean that not only are fewer staff having to care for more patients, using fewer resources, but a higher proportion of patients are presenting with cancers that are more complex, more expensive to treat and more likely to be fatal.

While Greece is undoubtedly at the sharp end of Europe's debt crisis, it is by no means alone. With austerity the prevailing watch-

word, public spending is being reined in everywhere. Although countries such as Spain, Italy, Portugal and Ireland are in the frontline, countries such as France, Belgium, UK and the Netherlands are not far behind. Even Germany, the strongest economy in Europe, has plans to cut public sector debt by €80 bn by 2014.

As healthcare accounts for a high proportion of public spending, and cancer accounts for a sizeable chunk of healthcare spending – with its need for complex multidisciplinary approaches to care, heavy use of expensive imaging techniques, and reliance

few scrub nurses. The inevitable result is long waiting lists. Spiliotis says he just told a patient diagnosed with colorectal cancer to come back in 45 days.

Waiting times for radiotherapy are even longer, he says. In the four main cancer hospitals and nine other public hospitals with radiotherapy equipment, the waiting list is three to four months. "It is very difficult to propose neoadjuvant chemoradiation for patients with rectal cancer with waiting times like that. So the patient has to get this treatment from private practice."

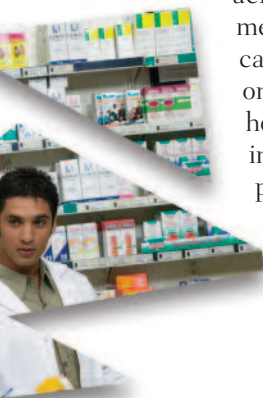
Supplies of essential cancer medicines, including Taxotere, Temodal, Avastin, Herceptin and Mabthera, are drying up, says Kathi Apostolidis, a breast cancer and patients rights advocate. She describes driving around the hospitals and pharmacies of Athens for a friend, in search of supplies of Zometa (zoledronic acid for controlling bone metastases). Pharmaceutical companies are insisting on advance payment from hospitals and public health insurance, she says, while pharmacies are refusing to deliver medicines to patients on credit. She believes patients are being held hostage

on some very expensive drugs – cancer services are under pressure as never before.

For patients, many of whom at the best of times feel they have to fight for quick access to the best treatments, the most urgent question is to what extent the financial pressures on Europe's cancer services are affecting frontline care.

In an effort to answer that question, *Cancer World* asked its European readers for feedback on how the European debt crisis is impacting on cancer care in their own countries. Ninety responses from 20 European member states suggest that there is a strong perception that the debt crisis is having a direct impact on patient care well beyond the countries facing the toughest cuts (see box *overleaf*). Drawing on comments appended to the survey and on interviews with some of the respondents reveals a patchy picture across Europe, but patterns are emerging.

ALAMY, CORBIS



WHAT THE SURVEY FOUND

A survey of *Cancer World* readers, asking about how public spending cuts are impacting on frontline cancer care, attracted 90 responses from 20 of the 27 European member states. Overall only 10% of respondents reported no impact on the quality of care cancer patients receive, with the vast majority reporting “some impact” (around 40%) or “quite an impact” (around 35%), and a little under 15% reporting “a huge impact”.

As might be expected, access to anti-cancer therapies (regardless of speed of access) showed the least impact, with almost 35% reporting no impact, a slightly higher proportion reporting “some impact” and only 25% reporting “quite an impact” or “a huge impact”. Access to other types of care, such as supportive care and rehabilitation, appears to be taking more of a hit, with only 20% reporting “no impact” and more than 40% reporting “quite an impact” or a “huge impact”.

Patients in many countries are also having to wait longer to get access to the services they need. The impact seems to be greatest for specific cancer therapies, such as surgery or radiotherapy, with almost 40% reporting a “huge impact” or “quite an impact” and only 20% reporting “no impact”. But many patients are also facing longer waiting times for seeing a specialist and getting the necessary diagnostic tests (around 25% and 30% respectively reporting the top two impact categories).

Interpretation of these findings are subject to all the usual warnings about self-selection of respondents and the subjective nature of the responses.

ACCESS TO DRUGS

Access to certain cancer drugs is changing across Europe. Fatima Cardoso, director of the Breast Cancer Unit at the Champalimaud Cancer Centre in Lisbon, reports that some drug companies have started to withhold supplies from hospitals that have been slow paying their bills. The government has been trying to intervene in cases where the hospitals have no alternatives, but Cardoso expects this problem to get worse.

Some doctors have been reduced to lying to patients because they don't want to admit there is no money to pay for the drugs they need, she says. Cardoso cites the case of a patient

whose bone metastases, which cause extreme pain and increase the risk of fracture, were being left untreated. “She had been told there are not enough data to support the use of bisphosphonates, because people are not frank enough to say: you should receive this drug but we have no money to give it to you.”

As with Greece, public cancer hospitals and oncology departments in Portugal are finding themselves flooded

with people who have had to give up private medical insurance. But even those who retain their private insurance can no longer afford the drugs they need, says Cardoso. “Even after so many years on the market, the price of trastuzumab is so shamefully high that most private health insurance barely covers the cost of one year of treatment, leaving nothing over to pay for the chemotherapy and all the other things patients need. For adjuvant therapy people sometimes do desperate things such as selling their houses to get the money for one year of treatment. But if you have to go on and on for as many years as possible, what can you do?”

In Italy, Anna Costato, who is being treated for advanced breast cancer, but is also a GIST patient advocate as a parent of a child with paediatric GIST, reports that access to new drugs takes longer and can depend heavily on where you live. This is because regional health authorities have the final say on what will be reimbursed, so a new medicine may be restricted even after approval by the European Medicines Agency and the national Italian agency AIFA.

Patients with rare cancers are hit particularly hard by measures that regulate the prescribing of drugs for off-label use. Costato believes that the measures, introduced in 2007, are now being wrongly used to restrict access to expensive drugs. She gives the examples of sorafenib (Nexavar), dasatinib (Sprycel), and nilotinib (Tasigna),



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which are recommended by the US National Comprehensive Cancer Network guidelines for patients with GIST who no longer respond to the only drugs approved for this indication, but which GIST patients have no access to in many regions of Italy.

Perhaps her greatest concern, however, is not so much the restrictions on medicines as the way financial pressures on doctors are leaving many patients feeling abandoned. “As an advocate of many patients with metastatic cancers, I find it very discouraging to realise that even some good oncologists are becoming more and more careful about spending money on treating terminally ill cancer patients.” Their primary concern seems no longer to be helping them to survive, says Costato, but rather how much it will cost. “Doctors should stay on their patients’ side,” she argues, “helping them to obtain proper treatments, and advocating for them, if necessary. They should leave accountancy to the accountants.”

In France, a country that has long prided itself on being at the forefront of adopting new cancer drugs, medical oncologist Jean-Yves Blay says the authorities appear to be quietly implementing a far more restrictive approach. A sarcoma specialist, he gives the exam-

ples of pazopanib (Votrient) and mifamurtide, which have both been rejected by the Commission de Transparence (which plays a role in reimbursement decisions in France) despite having been accepted for reimbursement by the UK’s NICE, which has tended to operate one of the more restrictive policies in Europe.

His worry is that this move towards – and beyond – NICE levels of restriction does not seem to be accompanied by similar levels of transparency, making it hard to comprehend or challenge decisions. “What isn’t clear in France is the process. Why is it being rejected? This is particularly shocking in the case of mifamurtide, which was reported to improve survival in one of the largest academic trials in osteosarcoma, admittedly with some methodological questions. This is a compound that is relevant to only around 100

patients per year. Yet the decision on this has left the drug in some sort of limbo – nobody can even buy it outside the system and give to a patient in France, meaning that we academics cannot even study it further. I had never seen that before in France.”

Ireland, meanwhile, has taken the slightly shocking, but arguably less opaque, step of more than doubling the height of the bar that new drugs have to jump before being accepted for reimbursement. In May, the value of an additional “quality-adjusted year of life” or QALY, which is used as the main measure to decide on reimbursement, was devalued by executive decision from €45,000 to €20,000 – a level which by today’s standards would seem completely unrealistic for new cancer drugs. There will doubtless be some room for manoeuvre – following a public campaign, Yervoy (ipilimumab)

for melanoma was recently approved on the basis of a QALY that was negotiated down from €150,000. At best it seems cancer patients who want access to new drugs may have to fight for it on a drug by drug basis.

Respondents from a number of countries also mentioned possibilities for running clinical trials – with all the associated advantages in terms of pushing up standards of care and early access to drugs – are increasingly restricted as a result of a more restrictive approach to new drugs combined with over-stretched staffing.

Who cares? There are concerns in some countries about the adequacy of care available to patients who are being sent home early to save hospitalisation costs



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LEVELS AND QUALITY OF STAFFING

Staff shortages and/or the de-skilling of certain roles due to budget cuts was another theme mentioned by many respondents.

In Portugal, waiting times for radiotherapy at public hospitals have been the focus of highly critical press coverage, because there are too few staff to operate facilities to full capacity. Patients are being badly let down says Cardoso. “I recently had a patient who had intensive bone metastases in her spine, particularly the cervical spine. She had been waiting for more than three months for radiotherapy. In the meantime, she developed leptomeningocarcinomatosis [affecting the tissue that covers the brain] and she is dying, at 37 years old.” Cardoso believes that while poor prioritisation of patients and poor organisation may be partly to blame, lack of personnel is also an important cause.

Costato in Italy talks of a steady decrease in the number of nurses, alongside a decrease in the number of hospital beds and length of hospital stays. What concerns her is that the care patients get on leaving hospital is largely given by low-paid untrained workers, which is impacting on the quality of care. Staff hiring is effectively frozen in hospitals, she says, which makes itself felt in longer waiting times for CT and MRI scans and for consultations with oncologists. Massimo Conio, a gastroenterologist in Sanremo, Italy, reports similar increases in waiting times for surgical procedures. Other survey respondents talk about staff shortages impacting on access to supportive therapies, “reducing the possibility of supporting the quality of life of children and families.”

Ingrid Kössler, a breast cancer patient advocate involved in Sweden’s National Cancer Control Strategy, reports similar concerns over the

increasing use of less trained nurse-assistants in place of nurses. Staffing is so tight, she says, that hospitals have come to rely on student nurses to cover absences during summer holidays. This year the student nurses are refusing to work unless they are paid a full salary; it is not clear how that will be resolved.

A scandal centred in Gothenburg over 60 patients with melanoma who were wrongly told they did not have cancer has put a spotlight on the strains personalised medicine is putting on pathology departments. Pathologists point out that they are being asked to perform many more tests for many types of patient than was the case a few years ago, and at current staffing levels they are finding it hard to cope. While Sweden is not one of the countries hardest hit by the debt crisis, says Kössler, the ageing population means that while cancer and other age-related chronic diseases are putting a greater burden on the health budget, there are now only two people working – and paying taxes – for each retired person, compared with a five-to-one ratio a few decades ago. A stagnant economy is not helping.

Comments from Ireland talk about a reduction in the number of “allied professionals” involved in the delivery of cancer care, including psychological support. A lower staff-to-patient ratio means less time spent with patients.

In the UK, survey respondents talk about reductions in follow-up visits and cutbacks in specialist breast nurses, scrubbed nurses (for operating theatres), “team members” and the administrative support necessary to free up clinical practitioners from bureaucratic functions. Nursing staff made it very clear at a recent conference that, in their experience, frontline clinical care is being directly affected by staff cuts despite assurances from the government to the contrary.



In the Netherlands staff cuts are reducing the healthcare support available to care for patients in their own homes.

Survey respondents from Spain mention longer waiting lists for diagnostic procedures and consultations with a specialist, as well as greater restrictions on access to health care from home support teams. Though it’s hard to quantify, it is clear that staffing levels are being steadily eroded through a virtual freeze on new appointments combined with the loss of many staff who were on fixed-term contracts. Cuts of 10–20% are planned for hospital staff who are not directly



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employed by the state (about half of the workforce). But Eugenia Trigos, a nurse specialist in paediatric haematology in Valencia, believes the worst may be yet to come. With Spain's economy exposed to a crisis that seems to have no end in sight, she says the real worry is what they don't know. “Every Friday there is a cabinet meeting and we have news about what the government is going to do. It is really horrible for us, what is happening now.”

COSTS AND BENEFITS TO PATIENTS

Responses to the survey also indicated that patients in many countries are being asked to pay more towards their

care and/or losing some of the social benefits they can expect to receive. In some cases the extra contribution is fairly minor – a few euros per hospital visit – and would be unlikely to impact on their care. In other cases there are concerns that additional charges may have a real and negative impact, for instance if they result in later diagnosis because patients delay visiting their doctor, or if the patient opts for cost reasons to forego medicines or services that could help them.

Many countries, including Spain, Portugal, UK and the Netherlands, are cutting back on reimbursement of transport costs for hospital visits. In the Netherlands, medical oncologist Elisabeth de Vries reports that patients requiring access to physiotherapy now have to pay for the first 20 treatments themselves, at €30/session, though patients with 'chronic' problems are exempted. Access to a dietician may be removed from the reimbursement list, and patients now have to pay for many of the self-care medications they need to cope with the side-effects of treatment. It is becoming more common to see patients foregoing the use of wigs, because these are no longer fully reimbursed. Similar

issues are reported from Ireland.

Cuts and restrictions in the benefits available to cancer patients seem to be a feature across many countries in Europe. In some countries these are hitting patients on oral therapies disproportionately, and in others they are also hitting families of paediatric patients. Though these cuts may not directly impact on the quality of health-care patients receive, they could further deter some patients from accessing therapies and services where they have to cover or contribute to costs.

WHERE NEXT?

Elke Van Hoof, head of the Belgian Cancer Centre, which coordinates the Belgian Cancer Plan, is convinced that having a detailed, fully budgeted cancer plan, subjected to continuous evaluation has been an important factor in protecting all aspects of cancer control from spending cuts. Over the past 10 years, she says, Belgium has invested a lot in cancer, including in more psychologists, social workers and nurses. She is proud

that last December the new government reconfirmed the budget previously agreed for the Belgian Cancer Plan.

Despite the financial crisis, she says, the government even allocated an extra budget for early and temporary access to therapies for unmet medical need and rare diseases, as well as extra money to pay for nutritionists.

“All the stakeholders, including the government, are trying



Wasted capacity. Staff shortages mean operating theatres and radiation facilities lie idle while patients have to wait longer for treatment



to keep the budget for care as it is now," she says. "We are told not to spend extra, but to try to be creative with what we have, so we are really evaluating the way we are reimbursing. Can we reduce the costs of reimbursement if we increase efficiency? Can we economise to have new funding to do new things?"

Greater integration is one focus point. "We pay for psychologists in cancer care, but can we also use them for other things?" Evaluating value for money is another. "Breast implants are very well reimbursed in Belgium, but they have a risk. Might it be better to use breast reconstruction with own tissue – isn't it more efficient because you have fewer complications and procedures in the longer term?" The option of adapting levels of reimbursement to encourage use of generics rather than expensive brands, where appropriate, is also under consideration.

One important spin-off of this proactive approach, says van Hoof, is that the Belgian Cancer Centre is able to back up its proposals for actions to include in the Cancer Plan with strong arguments and detailed data derived from the continuous evaluation of this plan. She believes robust cancer plans that have their own budgets and are closely monitored

and evaluated will be key to safeguarding the best quality care for cancer patients as Europe moves forward. She is glad that in Belgium they managed to get such a plan up and funded before the debt crisis struck.

But what of the countries that didn't? In Greece, John Spiliotis fully accepts that decades of virtually uncontrolled spending on healthcare, with the highest doctor-to-nurse ratio in Europe and no restrictions on prescribing, has contributed to the current crisis. He recognises the importance of a more sustainable, planned approach to delivering cancer services; he welcomes prescribing guidelines and greater use of generics; he is committed to cutting the list of lab tests, shortening the list of imaging procedures, cutting hospital stay, and using palliative rather than aggressive treatments near the end of life. He and his fellow surgeons are even shunning expensive technologies where it is safe to do so, going back to the manual procedures they haven't used for years, just to cut costs. "But we can't turn the clock back to the '60s or '70s in cancer treatments," he says. "This is a big problem

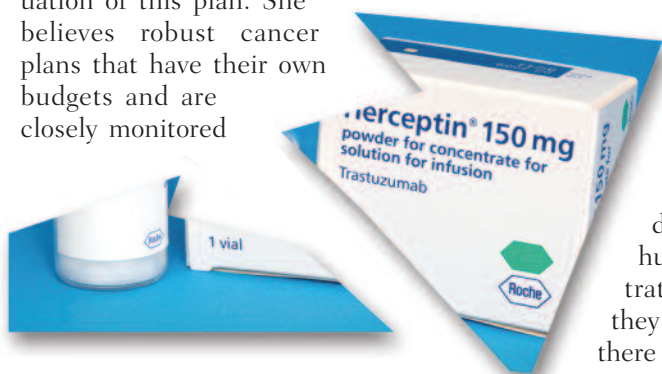
that started 30 years ago. We cannot correct it in the three to five years that Europe is demanding of us."

In Portugal, Cardoso believes there is huge scope for concentrating resources where they are most needed. "If there were proper guidance

so governments understand how to calculate overall cost-effectiveness, rather than just looking at the price of drugs, I think we could cut at least one third of the cost without affecting the quality of care," she says, "and we have to do it wisely and in a fair way." That guidance, she adds, has to come from collaboration between health economists and the people who deliver frontline care.

She is acutely aware of how much money is being wasted, for instance when vials of expensive drugs are opened, partially used, then thrown away because guidance says they can't be stored once opened. Coordinating things so that all patients receiving these drugs get them on the same day would help. However, drug companies must also cooperate in providing accurate data about the stabilisation of drugs and time-frames for use, she says.

In her own particular area, Cardoso is now focusing her efforts on advocating for all patients to be treated in breast units. "If you centralise treatment with people who know what they are doing, they will spend less," she says. She is also encouraging patient groups to speak with one voice and focus their demands on the bare essentials: access to best treatments; no cuts to medications that cannot be replaced; no cuts that affect the quantity and long-term quality of life.



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While she is more than ready to pull her weight within her own specialist area, Cardoso says this crisis cannot be resolved sector by sector. “You have to look at the whole picture. There are things you could really cut down, and others that you can’t because there is no option.” She questions, for instance, the high use of statins. “Statins are prescribed with no control at all, and are very often overused.”

Right now, however, patients in Portugal are threatened with the same crisis in getting hold of essential anti-cancer drugs as is already happening in Greece, and they need an urgent solution. Cardoso would like to see efforts, probably at EU level, to broker an agree-

ment with pharmaceutical companies that would allow hospitals that have been pushed into massive debt by the cuts to spread their payments over a longer time period. Even in the longer term she questions whether the current high prices of medicines are sustainable. “This is not just affecting Greece or even Portugal, Spain is already affected and it will soon start affecting Italy and France. This is a pan-European problem and we need a larger solution. Even if we think of it as a business problem, if the majority of countries are not able to pay, they are not going to sell.”

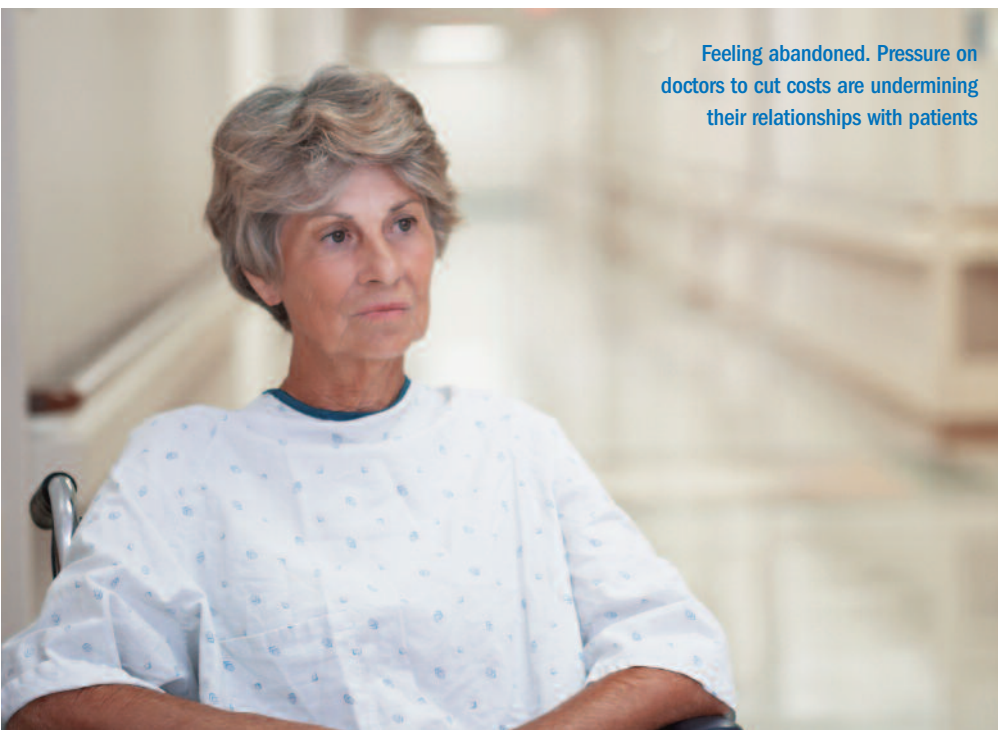
One possibility, she suggests, might be for the EU to expand the investment

it already makes in supporting pharmaceutical development, “in return for which the companies could put the drugs on the market at a lower price.”

There’s no question that this is a pan-European problem. The issue of how European countries – with ageing populations, a growing burden of chronic diseases, and rising costs of cutting-edge treatments – can provide the best possible care on a more sustainable basis has been around for decades. The current debt crisis and consequent austerity drive has merely brought it to a head, and whichever way the debates about austerity versus growth may go, healthcare rationing is now a reality.

Does that mean doctors will be forced to turn into accountants and put affordability before the interests of patients? Paradoxically, if the experience in Belgium as described by van Hoof is anything to go by, thinking more like accountants may be the only way doctors can safeguard their ability to fight for the needs of every patient. But instead of looking at a patient and wondering whether genuine opportunities to extend or improve their quality of life represent value for money, they need to be doing a lot more detailed monitoring and evaluation of the effectiveness and value for money of the treatments and types of care they deliver. Doing so will not just maximise the benefit patients get for the money spent but, as van Hoof showed, it also gives doctors and advocates essential evidence to help them argue for the level of resources they need... and to defend those budgets when they are under threat.

Feeling abandoned. Pressure on doctors to cut costs are undermining their relationships with patients



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