



Late diagnosis

Why does it happen? How can we do better?

Patients whose cancers are diagnosed late are more likely to require treatments that are more debilitating, more expensive, and yet less likely to result in a cure. With experts in countries such as Denmark and the UK now identifying earlier diagnosis as key to improving their cancer outcomes – with the potential to prevent an estimated 5000–10,000 deaths a year in the UK – the spotlight is falling on general practitioners, and their capacity to accurately spot suspicious symptoms and fast-track patients for further investigations or specialist consultations. International studies have identified the most common themes associated with delayed referral across cancer sites as “misdiagnosis, occurring

either through treating patients symptomatically or by relating symptoms to a health problem other than cancer... and a failure to fully or adequately examine patients, use of inappropriate or inadequate tests, and receiving or failing to follow up inconclusive negative or false-negative test results” (*BrJ Cancer*, 101:S92–S101). But GPs see several hundred patients with potential cancer symptoms every year, of whom only a handful will turn out to have the disease. They often face pressure not to overload specialists and diagnostic services unless there is a very strong basis for suspicion. Is it fair to lay the blame for late diagnosis on GPs? *Cancer World's* Anna Wagstaff asked two experts – a general practitioner and a specialist in gastrointestinal cancer – to discuss the issue.

Tina Eriksson

General Practitioner, Denmark, and member of the European Executive Board of the World Organization of Family Doctors (WONCA)

Finding the needle – the single patient at cancer risk – in the haystack of patients with temporary and benign symptoms, is at the core of general practice. So it is fair to hold GPs responsible for delayed referral and diagnosis of cancer patients. But the task is not easy. In Denmark, a GP with an average list size has 7500 patient contacts per year but will see only 10 new cases of cancer yearly covering all cancer types. Moreover, patients who turn out to be new cancer cases often present few and non-specific symptoms – only about half present an alarm symptom in the initial con-

sultation. So you have to investigate a lot of patients to find the ones with cancer.

Further complicating this picture is that many of the patients who seek help most often from their GP are unjustifiably anxious about having a serious disease, and may want to have tests done when there is no good reason. This anxiety can seriously affect their wellbeing, and their fears are often heightened rather than allayed by being tested. But of course these patients may suffer from cancer just like anybody else. So GPs as well as the health care systems are faced with real dilemmas here.

**Eric Van Cutsem**

Head of the Digestive Oncology Unit at the University Hospital Gasthuisberg, Leuven, Belgium

I agree that symptoms in cancer sometimes appear late and are often atypical, which is why they are recognised by the patient or the physician late. And when GPs are presented, for example, with functional abdominal symptoms – vague abdominal pain, a little anorexia, some dyspepsia – it can be difficult for them to filter those that might be related to a cancer from those that are not. However, sometimes there is a problem with inadequate examination. For instance, in the case of colon cancer, a patient may report rectal bleeding; the doctor sees the patient has haemorrhoids and concludes, “OK, it is probably linked to the haemorrhoids and it would not be appropriate to examine the colon.” So they decide not to test. Or when tests are done, they don’t always use the most appropriate ones. For instance, in patients with dyspepsia and a little bit of weight loss, they may do an ultrasound of the

pancreas; they find nothing, and they say the pancreas looks good. But ultrasound does not have perfect sensitivity – a CT scan is better in this situation. With some tests and examinations, physicians sometimes do two or even three screening examinations where nothing is shown, because of the lack of sensitivity.

So the problems are not doing the appropriate test, not going far enough with some patients, and in other patients doing a first test with a lower sensitivity and then taking the decision – OK let’s wait a couple of months, and if it deteriorates we will go further.

It’s true that there can be psychological downsides to testing. But not being tested when you have symptoms can cause greater anxiety. And failing to rule out cancer as a possible cause of symptoms could have greater consequences than creating anxiety. You have to weigh the risks against the benefits.



GPs can of course make mistakes like the one you mention and fail to investigate further the cause of blood in the faeces because they assume it must be explained by the presence of haemorrhoids. But it may also be that the patient is reluctant to be tested.

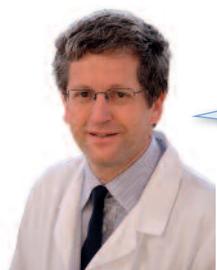
I would have to recommend a colonoscopy, which for the patient involves a day of liquid food and laxatives to empty the colon, and then being investigated quite far up through the rectum. It is not always easy to get patients to accept this unless they really feel there is a serious risk.

With patients whose intestines usually function like clockwork, it can be obvious when something is wrong. But a lot of people have benign colon symptoms most of their life, which fluctuate up and down, and that can hide more serious changes. You have to look for things like weight loss, or maybe new forms of dyspepsia that the patient didn't have before. Sometimes watchful waiting is the only thing you can do if a patient is not willing to go further and your suspicion is quite weak. You can take a blood test to check haemo-

globin levels and then ask them to monitor their weight and their symptoms and come back for further testing.

The lack of specific symptoms can also be a problem when it comes to referring patients for CT scans of the pancreas. Pancreatic cancer can be difficult to spot because there are so few specific alarm symptoms unless the patient looks jaundiced. There may be unspecific pain in the upper abdomen, which could be due to many reasons, some of them quite common. In Denmark, GPs cannot refer patients directly for a CT scan. We can refer them using a new fast-track cancer diagnosis scheme, but you would need a strong enough suspicion to use that option.

In my practice we see patients with symptoms that could be suspicious for cancer 10 times a week. If I were to refer all of them to the fast cancer track and all my colleagues did the same, the fast cancer track would break down next week. Already we are seeing long waiting lists, for instance, among patients with prolapsed discs, because the fast-track cancer diagnosis procedure is using up so much CT time.



Access to CT scanning will depend on the resources and system in each country. It's true that in some countries access can be difficult, but in other countries CT scans are overused. In Belgium it is not difficult to get patients referred for a CT scan, but there is still a judgement problem – people can make the call too late. It is essential to correctly evaluate the severity of the symptoms.

Regarding patients' reluctance to undergo a colonoscopy, there is a great problem with the public perception of this examination. There is no alternative

and it needs to be demystified so that people are less resistant.

Doctors need to take time to explain what is involved and that the patient has a lot more to gain than they have to lose. The most difficult part is the preparation, and doctors need to explain carefully how this should be done, because the colonoscopy itself will be much more difficult if the colon has not been adequately cleared. If it is well done the patient experience is not too bad. Information and communication are key, as well as good quality control.

I agree that good information and communication are essential, and you need to take time to build up a good picture of the symptoms and risk factors. This in itself can be a problem, particularly in countries like the UK where GPs are meant to spend no more than 10 minutes with each patient. It also takes time to talk to patients about why you think they may need further tests. When we first started referring patients to the fast-track cancer diagnosis, it took a while to get used to those conversations – at first it seemed a little harsh. Before, you would only raise the possibility of cancer with patients where there were stronger reasons for suspicion. Now we have to say, “We have this suspicion, which is not very serious, but we want to make sure, so I will send you now.” You need to adapt your communication, so you don’t scare people, but help them understand that it is a fast way to most probably find out that there is nothing wrong. If it is a cancer, it will be found earlier. It is also important to make sure that,

after they have been through the fast cancer track, whatever the outcome is, they either call or come back for an evaluation or chat.

IT systems may also have a role to play in reducing late diagnosis. There may be a combination of diagnosis coding, data capture and aids to diagnosis that in the quite near future may help GPs. In Finland they are working on a decision-making software that could help GPs be more systematic in reaching a diagnosis. While you are in consultation with a patient you can enter the symptoms on your computer and will get suggestions about possible diagnoses and other questions or investigations you can do. So, for instance, if you have unspecific pain in the upper part of the abdomen, you could be prompted to think: pancreatic cancer. IT systems can also make it easier to refer patients for diagnostic tests. Linked data systems can provide information about the local options for referrals, they can enable you to make the referral electronically, and the use of standardised criteria can ensure that only people who need referral will get it.



GPs have a crucial role in diagnosing cancers early. If GPs feel they don’t have enough time, they need to raise this within their health system and get changes. I understand it is very difficult for them. Specialists have very in-depth knowledge, but about many fewer things. GPs, in contrast, have to know about a wide range of things – not only all the different cancers, but everything else like diabetes and heart disease. Good interaction between specialists and GPs may help – I spoke to 200 GPs recently on the issue of familial risk, screening and other topics at an evening meeting and they clearly welcomed the chance to learn more.

Well-organised health services with adequate resources are also important to

ensure appropriate access to diagnostic procedures and prompt referral – it is clear that some countries have a poorer record than others on late diagnosis.

Full implementation of EU recommendations for quality-controlled population-based screening programmes would also result in more cancers being picked up early, and GPs have an important role to play here too. And society also has a role to play in raising general awareness about cancer: if people have a better knowledge of symptoms and understanding of their risk and of the importance of early detection, they will go to their GPs earlier, and be more open to undergoing further testing when it is recommended. ■