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Lesson of the Week

"Patients with terminal cancer" who have neither terminal illness nor cancer

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A person is terminally ill when after correct diagnosis and appropriate treatment the disease remains progressive, death is inevitable in the short term, and the practical need is for care not cure. We report on four patients wrongly referred for care for terminal cancer. Although they represent only a small proportion of referrals for hospice care (four of 1635 admissions), they were not terminally ill and the misdiagnoses were therefore important.

Some patients are referred for terminal care as a result of misdiagnosis

Case 1

A 70 year old man was admitted to hospital with a painful right hip and a pleural effusion. A pleural biopsy specimen was scanty, but two histopathologists thought that it showed small round cell malignancy, possibly lymphoma but more probably anaplastic carcinoma. His general condition was poor and he was given palliative radiotherapy to the hip, which improved the pain. Two months later he was admitted for hospice care.

Five months later he was referred back to hospital for reassessment. Although plasma electrophoresis showed an IgA paraprotein, the results of bone marrow aspirations were normal and no trace of malignancy could be detected. A total hip replacement was performed, and histological examination showed osteoarthrosis but no malignancy. A third histopathologist, asked to examine the original pleural biopsy specimen, also diagnosed small round cell malignancy. Three years later the patient was robust, cheerful, and living alone.

Case 2

A 75 year old woman had a haematemesis while being treated in hospital for heart failure. Endoscopy showed a gastric ulcer, which was considered by the endoscopist to be benign. The histologist, however, reported the endoscopic biopsy specimens as showing a poorly differentiated infiltrating, mucin secreting adenocarcinoma. This diagnosis was accepted. Bedbound and too ill for surgery, the patient was transferred to a hospice with an estimated life expectancy of three weeks. Her condition improved and she became cheerful and ambulant and gained weight. Five months later she was reviewed by the gastroenterologist, who considered the diagnosis to be still probably correct.

Three months later endoscopy showed an ulcer 5 mm in diameter on the lesser curve; the earlier biopsy specimens were reviewed and the report of poorly differentiated adenocarcinoma retracted. She was discharged home. Endoscopy three years later showed gastric scarring but no ulceration, and biopsy from a slightly irregular area and oesophageal brushings showed no evidence of cancer. Four years after admission to the hospice she was ambulant and cheerful, although she required treatment for cardiac failure.

Case 3

A 65 year old woman was referred from another hospital for hospice care four years after a cholecystoduodenostomy for pancreatic cancer. At operation the entire pancreas had been found to be affected by cancer, which was infiltrating the surrounding structures but had not metastasised to the liver or lymph nodes. The cancer was considered to be inoperable. A transduodenal needle biopsy of the pancreas showed no tumour, but the diagnosis was not revised in the light of this report.

Nine months later she had a coeliac plexus block for abdominal pain. Four years after the operation her multiple abdominal pains, which required regular oral and intramuscular opioids, led to referral to the hospice. One of us (WDR) saw her at home and thought she looked remarkably well for a woman with terminal pancreatic cancer. There was obvious stress within the family, and the patient, although ambulant, had refused to walk downstairs for three months. She knew that cancer of the pancreas had been diagnosed and that three years before her ovaries and right breast had been removed for breast cancer. She had not attended the outpatient clinic for three years.

In the hospice she was weaned off opioids in three weeks. Finding no evidence of breast or pancreatic cancer, her surgeon concluded that the

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"pancreatic cancer" found four years previously had been pancreatitis. Left loin pain persisted, but isotopic bone scanning and computed tomography yielded normal results. Acute on chronic pyelonephritis was diagnosed. Left nephrectomy by the anterior approach allowed the abdominal organs to be inspected; the pancreas appeared normal.

She was referred back to the psychiatrist who had seen her seven years earlier with intractable abdominal pain after her mastectomy. Initial progress was good, but five months later biopsy of axillary lymph nodes showed adenocarcinoma. In spite of treatment she deteriorated and 18 months later was truly terminally ill and died of breast cancer.

Case 4

Five weeks after being beaten unconscious in the street a previously fit 56 year old man was admitted to hospital with weight loss, anorexia, fever, and abdominal and chest pain. Extensive investigation including laparotomy showed no abnormality apart from an erythrocyte sedimentation rate of 112 mm in the first hour and a slightly raised alkaline phosphatase activity. Liver biopsy showed heavy haemosiderin deposits, especially in the portal tracts. The diagnosis was recorded as "pyrexia of unknown origin with hepatomegaly? cause."

Despite this uncertainty the family was told that he had cancer and a life expectancy of six weeks, and he was discharged to his daughter's home to die. Six months later his appearance was that of an old man, and he had bed sores and neuropathy. A consultant neurologist confirmed the complex neurological signs, thought them probably due to malignancy, and considered admission to a hospice appropriate.

His condition improved after his admission for terminal care, and the hospice arranged further assessment to ensure that the diagnosis of cancer was correct. He was noted to have been a heavy drinker. Extensive investigations again showed no cancer; his haemoglobin concentration was 102 g/l, erythrocyte sedimentation rate 130 mm in the first hour, and serum iron concentration 7·0 mmol/l. A urinary infection with klebsiella was treated. Isotope liver scanning showed ill defined areas of reduced uptake, although ultrasonography of the liver yielded normal findings. Electromyography and nerve conduction studies showed neuromyopathy consistent with an occult neoplasm. Liver biopsy again showed heavy iron deposits, mainly in the connective tissues and septa. His weight loss, neurological problems, and hepatic abnormalities were attributed to alcohol rather than occult neoplasia, and he was discharged back to his daughter's home. Six years after the diagnosis of terminal cancer he was well, had gained weight, and lived alone.

Discussion

The diagnosis of cancer is usually based on radiological and laboratory confirmation of clinical evidence. The confidence placed in a diagnosis will vary with the strength of the evidence that is available or that it is thought appropriate to obtain. Although a firm diagnosis is usually given by the histopathologist, certainty is not always possible. For this reason reports should perhaps indicate the pathologist's degree of confidence in the diagnosis. Residual doubts might be resolved by discussions between clinicians and pathologists. The possibility that errors will occur must be accepted. A rate of one in 400 is small but important, and because we may have missed other cases the true rate may be much higher. There were two basic causes of these mistakes: either incorrect histological reports or incomplete or misinterpreted evidence leading to the wrong diagnosis.

Incorrect histological reports may have several causes. The appearance of the tissue may be genuinely misleading: case 1 shows the well known difficulty of interpreting a scanty piece of inflamed pleural tissue. Mislabelling may cause not only a false positive result for one patient but also a false negative result for another. In case 3 a pancreatic biopsy failed to confirm the surgeon's operative diagnosis and the assumption was made that the biopsy needle had missed the tumour. Thus the wrong diagnosis was made because the true negative result was misinterpreted as a false negative result. In case 4 the diagnosis was based on the general appearance of the patient, the results of non-specific tests, and the failure to elicit any other cause for neuropathy. Some neuropathies may be the non-metastatic manifestation of malignancy, and many physicians would consider it unkind and inappropriate to embark on an invasive hunt for a primary tumour that is unlikely to respond to treatment. When the risk seems too great or the patient is too ill not performing a biopsy may be justified even if a tumour is suspected.

Doctors need to balance the benefit to the patient of accuracy and completeness of diagnosis against the unpleasantness, hazard, and expense of investigation. Whether more harm will result from a diagnosis of cancer when none exists or from accepting the diagnosis without rigorous proof needs to be decided for each patient.

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What steps should a doctor take to ensure that a medical report prepared for an insurance company or for an employer on an individual remains confidential?

Before deciding to release any information about the patient—whether this is to an employer or to an insurance company—the doctor must be satisfied that the patient has given a valid consent. For a consent to be valid it must be both free and informed. The mandate proposed within the complex, miniprint rules on the proposal form may no longer be sufficient to inform the patient. Patients do not always understand that signing this form gives the company permission to contact their doctor asking for considerable medical details, and more recently asking questions about the patient's sexual habits. If the doctor is persuaded that the individual has given a valid consent then a medical report may be completed. This must be sent to a named medical officer. All life insurance houses that are members of the Association of British Insurers know this and, in general, accede to this code. The code is, however, voluntary, but breaches reported to the central ethical committee of the BMA will be discussed with the council of the Association of British Insurers and the breach drawn to the attention of the insurance companies. This informal process usually leads to apologies from the insurance company and the introduction of an appropriate policy. Those companies which are not members of the ABI cannot be contacted through its council but individual approaches will be made on behalf of individual doctors by the central ethical committee secretariat.

If the insurance company or the employer refuses to submit the name of a nominated medical officer the doctor should send a note to the personnel officer indicating his or her willingness to submit a detailed report only when the company satisfies the doctor that conditions have been changed allowing him to fulfil his duty to maintain confidentiality of information on the patient. For a pre-employment medical report, where the prospective employee cannot start work until a report is received, it is reasonable for the doctor to advise the personnel department that the patient is fit to start work and to undertake the duties of the post, offering to send a full report to a medical officer, if needed.—VIVIENNE NATHANSON, BMA Secretariat.

A patient in his 50s who has had a plaque of Peyronie's disease removed from his penis still gets pain and discomfort. Will the pain improve and what is the likely course of the disease?

The local excision of a Peyronie's plaque from the penis whether undertaken for pain or deformity, or both, is almost invariably a less than satisfactory treatment. The pain associated with Peyronie's disease persists only as long as the disease is active, and this usually burns itself out. Certainly, time should be allowed for this to occur spontaneously. Concurrent treatment with potassium aminobenzoate or vitamin E has some support during this stage. The penile curvature on erection may be dealt with surgically, but this must not be undertaken until the degree of angulation has stabilised and any local discomfort settled. If the patient is having good, strong erections but the physical deformity of the penis is preventing penetration then Nesbit's operation affords excellent results. In this procedure segments of normal tunica are excised from the corpora opposite the concavity caused by the localised plaque or plaques of Peyronie's tissue (usually on the dorsum). The plaque itself is left alone. Not infrequently, however, secondary psychogenic impotence occurs in Peyronie's disease and surgical straightening of the penis alone will not resolve the patient's problem. In such cases the insertion of semirigid penile prostheses that are stiff enough to straighten the penis and allow intercourse are of established benefit. An alternative approach to treatment of this group of affected patients is to straighten the penis surgically and use intracorporeal papaverine to produce erections. Such treatment may well be required only over the short term to re-establish sexual intercourse if the cause of the impotence is psychogenic.—J C GINGELL, consultant urologist, Bristol.