Delays in diagnosing cancer
Threat to the patient-physician relationship

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That's probably been the hardest thing to accept about this whole cancer thing, is the fact that it could have been caught a lot sooner, and it wouldn't be metastasized by now. You know, he would have been saved.

—wife of a cancer patient

A long delay in the diagnosis of cancer can cause a crisis in relationships between patients and their family physicians. Both parties could be left shaken and worried, doubting themselves and each other but often unable to discuss what has happened. The relationship might rupture at the very moment when its resources for healing are most needed.

About 30% of a random sample of 202 patients with recently diagnosed cancer thought that it should have been diagnosed sooner and were more likely to be seeing a new family physician than those who felt their diagnoses had been made quickly. Family physicians need to recognize the potential crisis inherent in delayed diagnosis and be proactive in addressing it with their patients.

Nature of delay
Delay is a part of every diagnosis of cancer, and patients, doctors, and the health care system all contribute. The perception of whether delay is excessive is subjective. “Presentation delay” is the interval between when a patient first notices a symptom and his or her first visit to a doctor. Such delay can be lengthy. The mean presentation delay in a recent study of colorectal cancer cases was 10.8 weeks, while about 20% of women with symptoms of breast cancer delay more than 3 months before seeing a doctor. In breast cancer, older women and those who keep their symptoms to themselves have been shown to have longer presentation delays.

“Management delay” occurs at the level of physicians and the health care system and refers to the time between the first visit to a doctor, usually a family physician, and the start of treatment. New diagnoses of cancer occur infrequently in primary care. “Watchful waiting” is often used to define the seriousness of presenting symptoms that are nonspecific and might contribute to delays in testing or referral.

In other cases, incorrect attribution of symptoms, falsely reassuring test results, or unusual presenting symptoms add to delay. Waiting times for important diagnostic tests, specialist consultations, and cancer therapies are also important contributors. A recent study of colorectal cancer showed a median management delay of 19.5 weeks.

Effect of delay
A recent meta-analysis of breast cancer trials has shown that delays of more than 3 months from first symptom to treatment (so-called “total delay”) are associated with poorer 5-year survival. The relationship in other types of cancer is unclear. Shorter delay is associated with earlier stage at diagnosis in esophageal cancer, but no such relationship has been found consistently in colorectal, gastric, lung, or invasive cervical cancer. Survival appears to be driven more by the intrinsic aggressiveness of the tumour and the clinical stage at diagnosis than by delay itself, and in any one patient it is hard to assess the effect that delay might have had. Such uncertainty about the connection between delay and survival, however, is unlikely to relieve patients’ concerns that the delay might affect their chances of “beating” the disease. Longer delay is associated with increased psychological distress, and it is amid this distress that patients might examine the behaviour of both themselves and their physicians.
Delay and physician error

Substantial management delay can be viewed as an “adverse clinical outcome,” and in some cases a physician or patient might feel that the physician erred in not diagnosing cancer sooner. A medical error is an act or omission with potentially negative consequences for patients that would have been judged wrong by peers at the time it occurred. Most doctors admit to making errors, and many of these are delayed or missed diagnoses. Although experts emphasize the role of “system failure” in understanding why medical errors occur, family physicians attribute their errors largely to personal failings. Numerous studies document the self-doubt, guilt, and fear that error can engender in physicians. Emotional consequences for patients include anxiety, anger, and lack of trust and confidence both in their own doctors and in doctors in general.

Important steps in addressing delays

1. Assume that concerns about delay could be present whenever a diagnosis is serious. This ensures that physicians will remember to inquire about such concerns, particularly when they themselves have none. Physicians’ satisfaction with timely diagnosis might lead them to overlook presentation delays about which both patient and family could feel troubled.

2. If you perceive delay, assess whether medical error has contributed. Making a judgment about whether your actions fall below an acceptable standard of care is not easy. Doctors tend to be excessively critical of their own actions and to minimize the mistakes of close colleagues. For this reason, discussing the matter with a peer who is not a close colleague, or with a physician at the Canadian Medical Protective Association (CMPA) could be the preferred course. A doctor concerned about a potential error should also consider confiding in his or her spouse or in a trusted friend. This not only provides emotional support, but is also associated with making constructive changes in practice afterward.

3. Explore patients’ perceptions of delay in diagnosis. Entering into this discussion could be anxiety-provoking, even when a doctor does not feel there has been any great delay on his or her part. A “permission-giving” statement, useful in initiating discussion about other intimate subjects, might be helpful. For example: “Some people who have just been diagnosed with cancer wonder whether the diagnosis could have been made earlier. Is that something you’ve thought about?”

Family members should be included in such discussions whenever possible, as their perceptions sometimes differ from patients’ and will be important in how patient and family adapt to the new diagnosis. Discussions about delay should occur at an early follow-up visit and not when bad news is first being shared. When carefully done, such inquiry will no more cause a satisfied patient to doubt than asking about drugs and sexual activity will encourage these behaviours among adolescents.

4. If an error has been made, acknowledge it and apologize. Experts agree that full and prompt disclosure of error, together with an apology or expression of concern or sorrow, is the best course of action. It is clearly what patients want and expect and is consistent with a doctor’s moral obligation to further the best interests of patients. Disclosure and apology are also in a doctor’s best interest. Discussion between patient and doctor about the events surrounding the mistake might help patients be more understanding and bring emotional relief to the physician.

Physicians who handle errors in this forthright fashion might also be less likely to face legal action. It is the poor quality of physicians’ communication with their patients, rather than adverse clinical outcomes themselves, that often leads to malpractice suits. More than 40% of a sample of British patients and families taking legal action against their doctors stated that the lawsuit could have been avoided. An explanation and apology from the physician was the most common deficiency cited. Disclosing an error is an instance of “breaking bad news,” and guidelines for such discussions can guide a doctor’s approach. Medical error does not constitute evidence of professional negligence, and admissions of negligence are not recommended.

5. Respond to concerns about delay and recommit to the relationship. When patients blame themselves for delay in presenting with symptoms of cancer, physicians need to characterize such delay as normal, indicate the uncertain nature of its effect on their individual prognosis, and help them focus on treatment and recovery. Concerns about the doctor’s actions that seem ungrounded should be responded to in a non-defensive manner, explaining the thought processes that were followed and highlighting the challenges that cancer diagnosis often involves in primary care.

Most patients who believe a doctor has made a mistake will want to consult with another physician, and this option should be offered along with
any tests that might clarify the state of the patient’s health. If a physician’s office systems have been at fault, such as in the case of an overlooked test result, patients must be assured that improvements will occur because of the oversight. When problems in the health care system, such as delays in diagnostic imaging, have played a part in the delay, doctors should bring this to the attention of the proper authorities, with patients’ involvement when possible. The CMPA recommends that physicians also inform patients about any process through which their concerns can be investigated.

In all cases, the doctor should make a clear statement of his or her desire to continue caring for the patient. Telephone messages should be responded to promptly and longer follow-up visits booked to discuss the patient’s situation. A decision to part company over concerns about delay must be the patient’s alone and should be responded to graciously. Alternative physicians can be recommended, and transfer to a different physician in the clinic might give a patient the chance he or she needs, while maintaining relationships with other clinic staff.

Conclusion
Family physicians need to be alert to patient concerns about delay whenever serious illnesses, such as cancer, are diagnosed. Such inquiry needs to be routine and include other family members whenever possible. Long delays in diagnosis pose a threat to the health of the patient, the doctor, and their relationship. People facing new diagnoses of cancer need strong relationships with their family physicians. Addressing concerns about delay whenever cancer is diagnosed might strengthen and sustain a patient-doctor relationship that could otherwise be weakened or lost.

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