Delayed Diagnosis of Cancer in Primary Care: What do our Complaints tell us?

Anthony Hill, Health and Disability Commissioner
Assisted by Dr Katie Elkin, Associate Commissioner Legal and Strategic Relations and Natasha Davidson, Analyst - Research and Education

Complaints made to the Health and Disability Commissioner serve a number of purposes, including the opportunity for learning and quality improvement. This is true at the individual complaint level, where shortcomings can be identified in particular cases and changes made to address those issues. In addition, there is considerable benefit in being able to look across subsets of HDC's complaints in order to identify trends and patterns, and provide feedback to the sector on those findings.

The report

This week, HDC published its first in-depth topical analysis of such findings: "Delayed Diagnosis of Cancer in Primary Care: Complaints to the Health and Disability Commissioner: 2004-2013". This is an analysis of all complaints made to HDC in the last ten years in which the HDC expert clinical advisor considered that aspects of the primary care management had contributed to a delay in cancer diagnosis. We selected this topic for our first such analysis as it touches on three important issues:

- Primary care – the primary care sector is an important and high volume part of the New Zealand health care system. General practitioners perform around 15 million consultations per year, and often act as gatekeepers to the rest of the health care system.
- Diagnosis – concerns about diagnosis appear frequently in complaints to the HDC, with 36% of all complaints about general practitioners citing such issues.
- Cancer – cancer is the leading cause of death in New Zealand.[1] In many cases, earlier diagnosis leads to improved prognosis.

The results

Over the last ten years, 243 general practitioners have been complained about in relation to a delayed diagnosis of cancer, with the number of complaints per year increasing significantly over that time. While we note that this increase is consistent with general complaint trends, complaints about cancer misdiagnosis now comprise a significantly larger percentage of all complaints about general practitioners than was the case a decade ago.

Colorectal and lung cancers were the cancers most commonly at issue in the complaints, and the diagnostic delays were often lengthy. Comparatively, complaints about the delayed diagnosis of breast cancer were less common and involved shorter delays. These results were consistent with the international literature.

The factors leading to a delayed diagnosis most commonly identified by our expert clinical advisors related to:

- the cancer presenting with non-specific or atypical symptoms;
- poor communication with secondary care;
- appropriate referrals not being made;
- inappropriate reliance on negative test results; and
- the GP failing to adequately take, review or consider relevant patient history.

[1] Ministry of Health. Cancer: Registrations and Deaths 2011. Wellington: Ministry of Health; 2014

The delayed diagnosis factors observed varied by type of cancer involved. Delayed colorectal cancer diagnosis was significantly associated with the failure to conduct an appropriate examination, and the treating of symptoms in isolation, compared to other cancer types; while issues of co-morbidities drawing focus, and inappropriate reliance on test results were characteristic of complaints about a delayed diagnosis of lung cancer. We found that delayed diagnosis of skin cancer was significantly associated with the patient not reporting their symptoms, and delay in prostate cancer diagnosis was strongly associated with the failure to follow-up test results.

The learnings

Cancer can be difficult to diagnose. While the findings summarised above are not unexpected given the aetiology of particular cancers and the similar results reported in international studies, there are various learnings that arise, both for general practitioners and for their patients. One of the key objectives achieved by the HDC report is to bring together the clinical recommendations made in the cases, and make them more readily accessible, with a view to improving quality of care.

For general practitioners, the cases, and the trends and themes that emerge from them, suggest that additional focus could be given to:

- undertaking clinically indicated examinations and tests;
- examining patients in the context of their past history;
- ensuring comprehensive documentation is kept;
- being aware of the limitations of diagnostic testing (eg, false negative rates);
- considering all clinically relevant differential diagnoses;
- continuing to hold a suspicion for cancer despite co-morbidities;
- not treating symptoms in isolation;
- providing safety-netting advice to patients;
- having robust follow-up systems; and
- advocating for patients in the secondary care system.

For patients, diagnostic delay may be lessened by ensuring:

- attendance at follow-up appointments;
- the reporting of all symptoms to the general practitioner; and
- proactively following up on test results and referrals.

We are very pleased to have published this report, and trust that the information collated and shared through it will prove useful both for those providing services and for those who are recipients of those services.

The full report can be downloaded from HDC's website: www.hdc.org.nz