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Primary care delays in diagnosing cancer: what is causing them and what can we do about them?

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Introduction

Late diagnosis is a major contributing factor to poor cancer survival rates in the UK, and over 10,000 deaths per annum might be avoided if survival rates matched the best in Europe.[1] However, parts of the UK have achieved outcomes comparable to the best in Europe.[2] Understanding this gap is critical for places such as Tower Hamlets in East London, a multi-ethnic and deprived area, where one-year survival rates, a potential indicator of late diagnosis, are among the lowest in England. For example, the one-year survival rate for colorectal cancer is 65.8%, compared to the England average of 74.8%, and the highest rate of 82.7% (2007–2009 diagnoses). One-year survival rates for other cancers are similarly amongst the lowest ranking in the country.

Patient, doctor and system delays can all contribute to delayed cancer diagnosis with a significant proportion related to primary care.[3] While evidence is accumulating to explain patient delay, there is relatively less evidence exploring doctor or system level delays.

A significant challenge for the general practitioner (GP) is that cancer in primary care is a low incidence but serious disease. GPs can refer suspected cancer cases urgently via the two-week wait (2ww) system, which is based upon the National Institute for Health and Clinical Excellence (NICE) 2005 guidelines. These guidelines are often based on alarm symptoms, identifying patients who are high risk and symptomatic, while potentially missing 'low-risk, but not no-risk' symptomatic patients,[4] with the example of less than half of colorectal cancer patients having a symptom qualifying for urgent referral. While expediting the diagnosis in more advanced cancer may not yield a mortality benefit.[4]

Nine hundred thousand patients were referred by GPs via the 2ww system in 2010–2011, with 11% subsequently diagnosed with cancer[5] (5% in Tower Hamlets). A significant proportion of cancers reach a diagnosis by non-2ww referral routes, with a recent study showing that 24% of cancers were diagnosed through emergency admission, 26% 2ww referral and 21% standard GP referral, with proportions varying considerably with different cancer types.[6] As part of their gatekeeper function, GPs are under pressure to refer and utilise resources appropriately.

A 2008 systematic review of diagnostic error in primary care found that cancer was the commonest condition associated with delay in the literature,[7] and a 2011 review found no clear evidence for any interventions to reduce this delay.[8]

This essay aims to highlight clinician- and system-related factors that may be contributing to a delayed diagnosis of cancer in primary care. We present the context for why delayed diagnosis may occur, highlight areas potentially contributing to the problem and make recommendations for possible primary care interventions.

How well are GPs doing?

Results from the National Audit of Cancer Diagnosis in Primary Care and The Patient Experience Survey[9] indicate that the variance in number of GP consultations before referral is dependent on primary tumour site. Cancers such as breast and melanoma are most often referred after one or two consultations, while other cancers, such as myeloma, pancreas and lung had higher rates of three or more consultations before referral. This suggests cancers presenting with subtle non-specific clinical features, or in an atypical way, lacking red flags may be less likely to be considered as cancer and referred early by GPs. Increased delay is seen with non-white ethnicity, social deprivation/complexity, female gender and older age;[9] however, these factors do not explain the whole picture, and there may be other factors that are important to explore.

Clinician factors

Delays in primary care can be related to diagnostic error, with cancer the most widely identified condition associated with diagnostic error in primary care.[7] Features associated with diagnostic error include:

- Atypical presentations
- Non-specific presentations
- Very low prevalence of the disease in the general population
- Co-morbidity

Similar features have been found in primary care cancer significant event audits. The development of an initial set of diagnostic hypotheses by clinician is crucial within a consultation.[10] This has the potential to introduce cognitive bias, resulting in diagnostic errors,[10] while relying on previous experience and pattern recognition may not be sufficient for cases with the above characteristics.

Clinician and primary care system factors

Fragmentation of primary care. Primary care has become increasingly fragmented, with reduced partnership opportunities, and nationally around one-third of care is now delivered by sessional GPs (locums, salaried and retainer GPs) and is higher in some areas (e.g. Tower Hamlets 48% in 2012). Fewer GPs are working full time resulting in ‘open lists’, i.e. practice lists shared among several GPs, with few practices having clear protocols for list sharing. The practice of patients seeing one GP throughout their lifetime is diminishing, and patients report less continuity of care and more difficulty in seeing a consistent doctor.[11] This could potentially result in loss of clinician ‘gut feeling’, a combination of verbal and non-verbal cues, which requires experience and knowledge of the patient. This has been found to be discriminative in diagnosing some serious conditions including cancer.[12]

Time pressure. The UK has the shortest consultation times in Western Europe[13] with clinical decisions being made under acute time pressure. High level workloads may manifest in decreased patient-centredness which can be associated with decreased patient symptom reporting. In addition, where there is pressure on GPs to see many patients in the shortest possible time, the risk of error or missed or delayed diagnosis is intuitively higher and thresholds for intervention may rise.[14] This situation of demand on GPs is potentially worsened by contractual incentives, such as the quality and outcomes framework, which reward ‘technical care’ as opposed to its psychosocial components and may lead to the dominance of a clinician led agenda.

Primary care system factors

Support systems in primary care. Support systems related to professional support, continuity of information, diagnostic aids and safety netting protocols are particularly relevant to the diagnosis of cancer. With higher numbers of sessional GPs, there is a potential for professional isolation and for limited access to information about education, clinical systems and professional support structures.[15] Clinical commissioning groups (CCGs) are evolving, and their communication systems may not prioritize a comprehensive updated list of all GPs working in their area, or a single point of accountability for maintaining this. At a practice level, there can be uneven systems for cascading information, and GPs may miss out on updates of referral pathways, or new services.[15] Reaching and updating all GPs within an area is therefore challenging.

There are multiple electronic health record (EHR) systems in use within UK primary care. Many GPs are self-taught on these systems, which may have implications for reliability of data coding. Unless clear and consistent protocols are adhered to across providers and within a practice, there are dangers of information ‘slipping through the net’.

Cancer risk assessment tools have been developed (e.g. QCancer); however, these are currently yet to be nationally implemented within normal workflows, missing an opportunity to alert GPs to consider cancer. Safety netting, i.e. communicating to the patient the existence of uncertainty in any diagnosis and outlining exactly what the patient needs to look for, within a specific time frame, and how the patient can seek further help, has been found to be variable in case reviews (e.g. in Tower Hamlets).

Primary care resources and gatekeeper function. Ninety percent of NHS patient encounters occur within primary care with less than 10% of the budget.[16] The current financial constraints are set to continue with a predicted shortfall of GPs. The gatekeeping system in itself may also be part of the problem. Countries with a gatekeeper system have been shown to have relatively lower one-year relative cancer survival.[3]

So what could be done?

The following options may prove fruitful:

1. Re-establish relational continuity of care:
   - Small GP teams – Relational continuity of care refers to patients seeing the same doctor or other clinical practitioner with whom they build a relationship over time. Limiting patient lists to the minimum number of GPs with clear hand over arrangements and regular review of complicated patients. This has benefits beyond cancer and impacts on sharing the responsibilities of managing complex patients. It also impacts on minimising the isolation GPs have experienced in managing difficult patients.
   - Longer consultations – These tend to enable the GP and patient to address the wider patient care agenda and contribute to improved outcomes,[17] though a shorter consultation may reach a similar outcome if the patient and doctor already know each other well and the patient feels able to communicate key personal information.
2. Information gathering, dissemination and continuity:
   - Recognition of the potential for diagnostic error, and strategies to reduce this, such as a willingness to search for alternative explanations for the complaints of patients.
   - Ensure wide dissemination of information reaching all GPs, encourage and reward commitment and continuity and ensure reasonable case loads which allow curiosity to be maintained. CCGs may not yet be prioritizing an understanding of the demographics of their GP workforce and how this impacts on the provision of care.
   - Information Technology training and updates to minimise coding inconsistency between GPs, and formal training to be included in the GP curriculum is needed. Documenting and coding patients' reason for encounter, which can be in the form of symptom, a diagnosis or a request for intervention, and not just diagnostic codes in the EHR, allows for a deeper understanding of the diagnostic process, improving the quality and accuracy of diagnoses, and enhances their usefulness for research and for decision support.[18]
   - Patient held records may improve continuity. If patients can access all the information about themselves, make appointments, order repeat prescriptions and access information and decision support tools, this can increase health literacy, improve concordance and accuracy in the records as well as a trusting adult-to-adult relationship that itself improves health and outcomes.[19]
3. Threshold for suspected cancer referral:
   - Cancer risk assessment tools, such as QCancer are being piloted in general practices, which may help in identifying patients at higher risk and prompting referral, although recognition of the complexities of rolling out these tools should be acknowledged.
   - NICE is reviewing the current urgent suspected cancer referral guidelines and is due to update these guidelines in 2014.
4. Improving safety netting:
   - In line with the National Cancer Action Team's recommendations,[20] safety netting should become a routine part of care. For this to be effective, however, both continuity in relationships and continuity in information are paramount.

Some concluding thoughts and questions

Early diagnosis is the result of the best interaction between patients and their GP. This paper has focused on clinician and system factors within primary care. Some of the interventions discussed could be implemented at an individual GP and practice level, such as practices aiming to increase relational continuity of care, improved information dissemination, consistent use of EHR systems utilising reason for encounter and clear safety netting. Recent changes in the structure of the NHS and the continuing pressure of limited resources and increasing demand means that some proposed interventions such as information dissemination across the new structures (e.g. CCGs) and increasing consultation length may be difficult to implement. A continued focus on primary care research (e.g. Cancer Research UK (CRUK), National Awareness and Early Diagnosis Initiative (NAEDI)), and primary care system improvements including implementation and evaluation of cancer risk assessment tools are essential. These measures could have a wide reaching impact not only on early diagnosis of cancer and survival but also on primary care as a whole, while also contributing to a safe, productive and rewarding working environment for GPs.

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