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EDITORIALS

Why can't we improve the timeliness of cancer diagnosis in children, teenagers, and young adults?

A comprehensive programme of research is needed to find out

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More than a third of young people attending this year's Teenage Cancer Trust conference, "find your sense of tumour," were diagnosed through emergency presentation, with a quarter having previously visited their general practitioner with symptoms. This has resulted in a considerable amount of "GP bashing" by young people and an angry but passionate call for interventions to improve the timeliness of cancer diagnosis. The problem seems to be real, but the research evidence is missing.

In the United Kingdom, five year cancer survival for children and young people (0-24 years) varies between 50% and 95%, with survival in some cancers hardly having improved over the past two decades.[1 2] Although cancer is the leading cause of death from disease in this age group, it is rare—around 3500 cases a year. Morbidity from both the treatment and disease is considerable, and interruptions to social development, education, and employment are likely. Caring for a child or young person with cancer can cause serious stress within the family, and the economic consequences for the family and society are considerable.

Evidence exists that children and young people experience a prolonged diagnostic journey,[3] with wide variations in duration of symptoms and time taken to investigate and treat. Some of the delay occurs in primary care. People aged 16-25 years are twice as likely as older adults to have three or more GP consultations before referral.[4] They are also more likely than adults to be diagnosed through emergency presentation.[5] Many describe their diagnostic experience with a sense of loss, anger, and frustration, and studies have found that perceived diagnostic delay is associated with increased anxiety in patients and parents.[6 7]

Young people are unaware of the more common cancers that affect their age group—embryonal, brain, and germ cell tumours; leukaemia; lymphoma; sarcomas; and other solid cancers.[1 2] This means that even if they attribute a symptom to an illness, it is unlikely to be to cancer. A quarter of young people cannot name a cancer symptom, and confusion about cancer abounds—for example, some think that hair loss is a symptom.[8] If symptoms are judged as serious, barriers to seeking help include worry about what the doctor might find (72%), embarrassment (56%), or being too scared (56%).[8] This, coupled with inexperience of communicating serious symptoms, may further impede the diagnostic process.

Most patients consult their GP about their symptoms. In adults the predictive value of 'alert' symptoms has generated risk assessments for some cancers.[9] Analysis of pre-diagnostic consultations in children finds a positive association between "alert" symptoms and a cancer diagnosis, although the positive predictive values of individual symptoms are low.[10 11 12] Even when specified alert symptoms are combined with multiple consultations over a short time, the probability of a cancer

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diagnosis ranges from 11 per 10 000 children to 76 per 10 000 [12] with similar results reported for young people.[11 12]

A recent *BMJ* paper highlighted the problems faced by healthcare professionals in identifying children and young people with brain tumours.[13] For 10 000 children presenting to their GP with visual symptoms, only six will be diagnosed as having cancer within three months. If the child also had multiple consultations, this increases to 23/10 000.[12] Although a considerable increase in the likelihood of a cancer diagnosis, for proponents of a "three strikes and refer" policy in young people with alert symptoms, the low predictive value is disappointing and likely to overwhelm services and cause unnecessary anxiety and investigation.

What can be done? Young people and their parents want early diagnosis to become a research priority.[14] Whether timely cancer diagnosis in this age group affects survival is unknown, but, improvements in the timeliness of the diagnostic process may reduce treatment related morbidity and psychological distress associated with a bad diagnostic experience. Research directed towards optimising the diagnostic experience and identifying relevant outcomes for children and young people is urgently needed.

From a medical perspective, an "optimal diagnosis" includes starting treatment before delays have affected outcomes. For a patient, however, optimal diagnosis further implies the calming of fears which a cancer diagnosis generates. Once diagnosed, patients invariably view their diagnosis within the context of their medical history. Consequently, they may think of their diagnosis as suboptimal, especially if they can relate symptoms of an earlier illness to cancer, regardless of how realistic this may be. This can cause young people to question themselves—whether they should have taken symptoms more seriously—and the medical professionals overseeing their care. Thus, the quality of communication with all the medical professionals encountered during the diagnosis pathway may determine how patients view their diagnosis. As a result, even an optimal diagnosis, from a medical viewpoint, can still be perceived as suboptimal by the patient.

Much of the existing evidence has been generated from research on adults with cancer, which limits its generalisablity. We need researchers and funders to respond to the specific needs of this age group. A comprehensive programme of research is needed to identify which parts of the diagnostic journey matter most for young people and to suggest which interventions might best inform policy and practice. Then these interventions need to be tested quickly and robustly. The "find your sense of tumour" audience deserves no less and will expect to be vital and enthusiastic contributors to such important work.

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