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Investigating cancer symptoms in older people – what are the issues and where is the evidence?

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Introduction

Some may argue that when an older person presents to primary care with symptoms which may represent cancer, they should not be investigated differently from younger patients. We think that cancer risk management in older people requires a different, more personalised approach. Recently there has been a significant increase in knowledge regarding the management of possible cancer symptoms in primary care (1). This knowledge however, is not age related, and research on the specific diagnostic management of symptomatic older people is scarce, despite older age being associated with greater likelihood of developing cancer. This editorial will explore the issues that are specific to the management of older people with a potential cancer diagnosis, identifying gaps in our knowledge base and highlighting the need for more research to underpin good practice.

Current evidence and best practice

The National Institute for Health and Care Excellence (NICE) released guidelines in 2015 on the recognition and referral of suspected cancer in primary care. While the guideline provides lower age limits for investigation and referral of specific symptoms it has no upper age limits, it does not specifically discuss older age when recommending investigation or referral, nor does it consider frailty, quality of life or comorbidities. The guidance recommends discussing patients' preferences about investigations and their potential risks and benefits, but states that there is no evidence on the information needs of older people. In fact, older people are significantly underrepresented in the evidence base underpinning the NICE guidelines. If colorectal cancer is taken as an example of a cancer with a peak incidence in 85-89 year olds, the guidance is based on 31 studies. In five of these studies older patients were specifically excluded. For the other studies, where data were available, the average age of the patients was significantly lower than the average age of colorectal cancer diagnosis in the UK.

Increasing age, increasing frailty and increasing cancer risk

Ageing is a very individual process and from a health perspective there is no 'typical' older person. However, for research and administration purposes 'older adults' are arbitrarily defined as individuals aged 65 years and older. With the rise in life expectancy, the ages and profile of adults included in this age category is widening. Cancer is a disease of older people with cancer incidence rates in the UK peaking at 85-89 years old and worldwide cancer incidence rates increasing most rapidly in the over 70 age group (see figures 1 and 2) (2, 3). In the UK, most cancers are diagnosed following symptomatic presentation to primary care. This is particularly true in those aged 75 and over who are not routinely screened for cancer due to upper age limits in the national screening programmes. It is established that older people have a lower awareness of potential cancer symptoms, and a lack of awareness that increasing age is a risk factor for cancer (4). The time from first presentation with symptoms in general practice to a diagnosis of cancer increases with age (5), and older patients are less likely to be referred on a two week wait (2ww) cancer referral, yet are

much more likely to be diagnosed with cancer when a 2ww referral is sent. General practitioners face a challenge, managing the increasing numbers of older patients with a potential diagnosis of cancer, often with a poor prognosis, with little scientific evidence to guide decisions.

Older patients have increased risks

In most patients, early stage diagnosis is important and is associated with improved survival (6). However, in older people potential survival benefits are shorter due to natural life expectancy and older cancer survivors have increased needs, reporting more multimorbidity and poorer health outcomes (7). The incidence of frailty increases significantly with age, as does the incidence of morbidity and mortality, resulting from invasive investigations and cancer treatment in frail patients (8). The imperative to diagnose cancer early must therefore be balanced with the preferences of older and frail patients. A systematic review found that older age was linked with a preference for quality of life rather than length of life (9). Furthermore, patients over 70 have been shown to be less likely to want investigations for possible cancer symptoms and to accept a higher risk of cancer being undiagnosed (10). Older people want to be able to do the things they consider important for as long as possible, therefore any investigation, referral or treatment should "add life to years, not years to life"(11). However, in some individuals even a marginal gain in life expectancy could be important, enabling the patient to attend a family wedding, or meet a new-born grandchild for example. An additional consideration is that investigations for cancer are rarely available in the community and often require more than one visit to hospital. This may be particularly challenging for frail older people, particularly those living in care homes or who have limited family networks to support attendance at hospital appointments.

Difficult decisions, balancing needs, and informing decisions

GPs will increasingly encounter older people who present with symptoms which could be due to cancer. The decision on whether and when, to investigate or to refer these patients is complex and should take into account the patient's preferences and in some cases those of their family. When discussing this decision with patients, there is a need to consider issues such as the patient's quality of life, comorbidities and degree of frailty and how potential investigations may impact on these factors. The value to patients of having a diagnosis should be considered, and how a diagnosis may provide better access to palliative care, specialist nurses and charitable support which may improve symptomatic management and quality of life (12). Referral for suspected cancer symptoms by GPs initiates a diagnostic pathway in secondary care which may escalate from simple to more invasive investigations, followed by biopsies and treatment. However, as after the start of the pathway, continuation is rarely discussed, it is the GP who plays a crucial role in explaining the pros and cons of the initial diagnostic referral.

Whilst frailty is increasing, there remains a significant proportion of older people who are healthy and do benefit from a timely cancer diagnosis. Therefore, guidance that considers age as a strict cut-off point is ethically unjust and is unlikely to be helpful in defining new care pathways for the heterogeneous banner of 'older people'. What is needed is shared decision making (SDM) with patients after evaluating the pros and cons of diagnostic referral on an individual basis (11). SDM is a key part of health policy in the UK with the most recent NHS Long Term Plan advocating personalised care across the entire health and care system. This may be particularly challenging in older people, as research demonstrates that they may be less willing to actively participate in medical decisions. Other barriers to SDM include a lack of GP time and patient comorbidities such as dementia, or stroke which may impact on understanding, communication and decision-making abilities. However, SDM should be encouraged with older patients and this shared care should

continue after the initial decision, through cancer investigations and treatment, ongoing monitoring and palliative care.

Specific research is needed for older people

Currently GPs use their own judgement to make difficult decisions around referral for cancer diagnosis, and use generic, not age specific guidelines to support them. NICE guidelines advocate referral regardless of age or frailty, leading to potential harm from over investigation and over diagnosis without any clinical benefit. The guideline introduced the concept of cancer risk, suggesting that patients with a risk of 3% or greater be referred for further investigation. Cancer risk increases with age, as does the risk that an 'alarm' symptom may be due to cancer, as a result a greater proportion of older people will have a cancer risk greater than 3%. However, it may be relevant to reconsider the definition of adequate and timely diagnosis and treatment of cancer, given the impact of comorbidity, physical and mental decline on life expectancy, and preferences of older people for accessing diagnostic and therapeutic interventions. To inform and improve care, more research is urgently needed on frail older patients and their carers' thoughts on, and experiences of, investigation and referral for cancer. This will support greater understanding of the risks and benefits of a cancer diagnosis for older people with frailty or comorbidity and improve informed shared decision making with older people.

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Figure 1
Cancer Research UK. *Cancer statistics*. (2018)
https://www.cancerresearchuk.org/health-professional/cancer-statistics/incidence/age

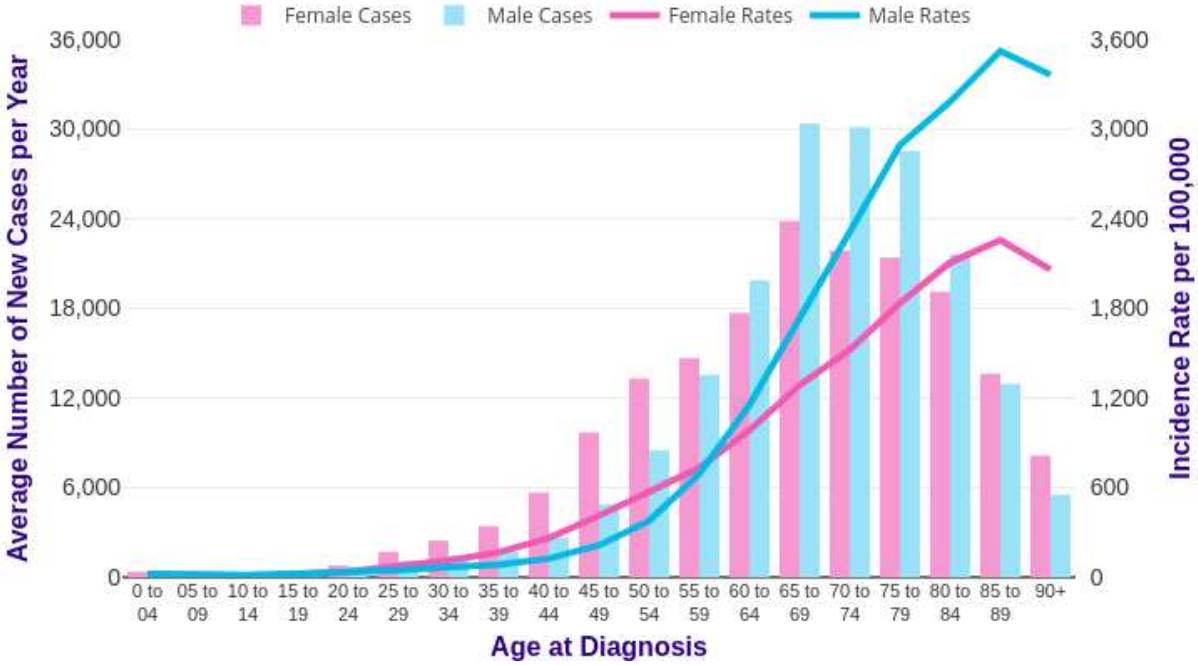
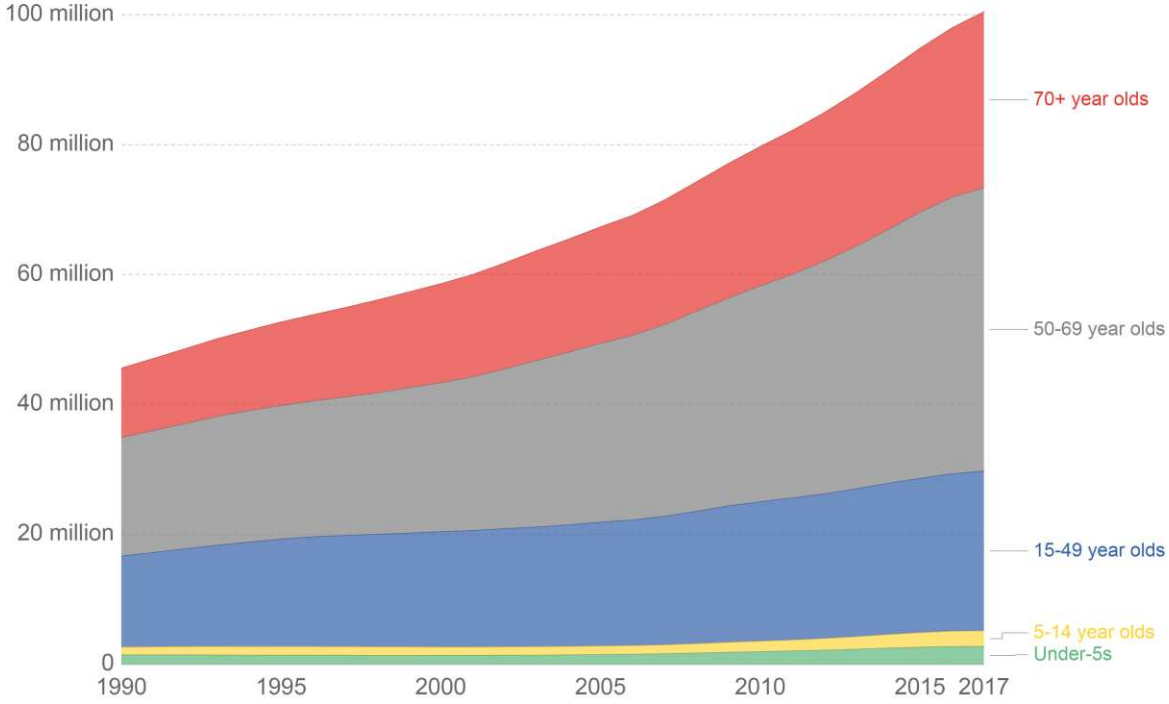


Figure 2
Our world in data, using stats from Institute for Health Metrics and Evaluation. Global Burden of Disease Collaborative Network. Global Burden of Disease Study 2017. Seattle: 2018.
https://ourworldindata.org/cancer#cancer-prevalence-by-age

Number of people with cancer by age, World

Total number of people with cancer, differentiated by age. This is measured across all cancer types.



Source: IHME, Global Burden of Disease

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