

Protecting and improving the nation's health

Health Inequalities: Cancer

Introduction

Cancer is the second leading cause of death globally¹. In the UK there were 359,960 new cases of cancer in 2015 and 163,444 deaths from cancer in 2016 which accounted for 28% of all deaths².

Prevalence and risk factors

The incidence and pattern of cancer amongst people with learning disabilities is rapidly changing partly due to increased life expectancy^{3 4 5 6}, as the incidence of cancer rises dramatically with age¹.

Epidemiological studies from other countries suggest that the incidence of cancer among people with learning disabilities is comparable with that in the general population ⁷ ⁸.

Data from GP records for 47% of people in England in 2017/18 indicate that the number of patients with a recorded learning disability who had a diagnosis of cancer was 1.5%, compared to 2.7% of other people⁹. However, mortality rates from cancer among people with learning disabilities in England have been found not to differ from those in the general population¹⁰ ¹¹.

It would not be meaningful to propose a tumour profile for the entire heterogeneous population of people with learning disabilities¹². However, studies that specify types of cancer deaths indicate that most underlying causes of cancer deaths for people with learning disabilities are from diseases of the digestive organs¹³. This differs from the pattern of cancers found in the general population, in whom lung, breast and prostate cancer predominate. Oral tumours in patients with learning disabilities may be less frequent than in the general population¹⁴. The prevalence of cervical cancer is lower in women with learning disabilities than other women^{7 8 15}. Men with learning disabilities may be more likely to develop testicular cancer than other men^{16 17}. Down syndrome is undoubtedly associated with increased risk of testicular cancer¹⁷. The incidence of acute leukaemia is elevated among people with Down syndrome, whereas solid tumours are uncommon¹⁸. People with fragile X syndrome may be at lower risk of some types of cancer¹⁹.

Health inequalities: Cancer

Around one-third of deaths from cancer are due to the 5 leading behavioural and dietary risks:

- high body mass index
- low fruit and vegetable intake
- lack of physical activity
- tobacco use
- alcohol use¹

People with learning disabilities are less likely to smoke or drink alcohol, but are more likely to be overweight or obese, to have poor diet and to do insufficient physical activity compared to the general population²⁰. The risk for lung cancer in people with learning disabilities strongly correlates with the severity of learning disabilities, with smoking being more common among those with mild learning disabilities²¹.

There is a high prevalence of Helicobacter pylori in people with learning disabilities, a class 1 carcinogen linked to stomach cancer, gastric ulcer and lymphoma among people with learning disabilities²² ²³ ²⁴. It has also been hypothesized that digestive system cancers may be influenced by gastrointestinal tract dysfunction, gastro-oesophageal reflux disease, chronic constipation and poor diet⁶. These health risks are common in people with learning disabilities.

Impact on people with learning disabilities

Cancer is a leading underlying cause of death among people with learning disabilities¹³. Neoplasms have been found to be the third most common cause of death of people with learning disabilities in England¹¹. For people with learning disabilities, tumours are more often diagnosed at a late stage^{14 17}.

The way that people with learning disabilities express pain and distress is highly individual²⁵. People with learning disabilities might not express pain or report changes in their physical appearance which can lead to substantial delays in symptom presentation and diagnosis²⁶.

Residential care staff may lack knowledge of the signs and symptoms of cancer, as well as the risk factors for certain cancers²⁷. Recent analysis of NHS Hospital Episode Statistics suggests that people with learning disabilities are far more likely to die from testicular cancer than the general population, with a one in 10 chance of dying from the cancer, as opposed to a one in 36 chance in the general population¹⁶. Analysis of data regarding other types of cancer (for example prostate, breast and colorectal cancer) is ongoing¹⁶.

Healthcare and treatment

Cancer mortality can be reduced if cases are detected and treated early¹. People with learning disabilities in the UK are significantly less likely to receive NHS screening tests for cervical, bowel and breast cancer than those without learning disabilities²⁸. At a national level, reported cancer screening coverage for eligible people with learning disabilities in 2012/13 was substantially lower than for the population as a whole (cervical cancer screening 27.6% of people with learning disabilities vs 70% of total population; breast cancer screening 36.8% vs 57.8%; bowel cancer screening 28.1% vs 40.5%)²⁹.

The Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) reported that the greatest difficulties for people with learning disabilities appeared to be with access to bowel cancer screening³⁰. More recent 2017/18 data from approximately half of GP practices in England report the following rates of cancer screening in the last 5 years (cervical cancer screening 31.2% of people with learning disabilities vs 73.2% of population without learning disabilities; breast cancer screening 52.5% vs 68.0%; bowel cancer screening 77.8% vs 83.7%)⁹. There is some anecdotal evidence that screening liaison nurses could improve participation in cancer screening³¹.

There is little research regarding the treatment of people with learning disabilities who have cancer. Caregivers may feel uncomfortable and unprepared to support the patient, and attempt to protect the patient from negative effects of cancer by limiting truth-telling²⁶. Oncology nurses may perceive themselves as lacking confidence and being insufficiently trained to recognise and meet the needs of cancer patients with learning disabilities³². There is a need to develop effective ways of supporting health care professionals in enhancing patient-centred skills with this population²⁶.

Social determinants

The incidence and mortality of cancer is considerably higher in deprived groups compared with more affluent groups³³. This has been attributed to environment, lifestyle, biological effects, access to health care and health seeking behaviour³⁴. However, there is no known data specifically relating to people with learning disabilities.

The quality of social care support received and access to appropriate healthcare is likely to impact on the prevention and early diagnosis of cancer in people with learning disabilities but there is no known research that has specifically addressed this issue.

Health inequalities: Cancer

Resources

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