Knowledge & Library Services (KLS)
Evidence Briefing

Which population groups are more likely to delay presentation with cancer symptoms and are more frequently diagnosed with late stage cancer, and why?

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Which population groups are more likely to delay presentation with cancer symptoms and are more frequently diagnosed with late stage cancer, and why?

**Question**

This briefing summarises the evidence on delayed cancer presentation and late stage cancer diagnosis from January 2008 - January 2019

**Key messages**

- Amongst all the population groups considered, the main reason for delay in presenting with cancer symptoms is lack of knowledge and not recognising cancer symptoms.

- Opportunities for diagnosing cancer in younger people are frequently missed in primary care. This may in part, be because they fall outside referral guidelines and targeted screening programmes.

- Black people with colorectal cancer are more likely to present with late stage cancer irrespective of affluence or deprivation. This may be due to factors such as cultural attitudes, beliefs and embarrassment, as well as limited access to healthcare.

- Stage of cancer at diagnosis varies between different ethnic groups. This may be due to the degree of engagement in health promotion initiatives and screening programmes.

- Poorer survival outcomes for women with bladder cancer are not explained by delays in presentation and diagnosis alone – biological factors also have an important role to play in survival outcomes.

- Poverty is associated with an increased risk of late stage melanoma presentation even when adjusted for age, sex, race and rural gradient.

- Women need to present with symptoms for bladder cancer more frequently than men in primary care (more than 3 pre-referral appointments) before being referred to secondary care.
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**Background**

The United Kingdom (UK) lags behind other European countries in terms of positive cancer outcomes(1, 2). Delays in presentation of cancer symptoms and diagnosis of late stage cancer are associated with poor outcomes and higher rates of mortality(3, 4). There is evidence to show that socioeconomic status, ethnicity, age and gender are risk factors for delay in presenting with cancer symptoms and being diagnosed with late stage cancer(5, 6). This briefing summarises the available evidence on the groups affected by inequalities in cancer presentation and diagnosis and considers some of the reasons, to inform strategies aimed at reducing mortality in these populations.

**Age**

According to a study assessing cancer specific-variation in emergency presentation, younger people are at greater risk of emergency presentation for acute leukaemia, colon, stomach and oesophageal cancer, whilst older people are at greater risk of emergency presentations for laryngeal, melanoma, thyroid, oral and Hodgkin’s lymphoma(7).

Colorectal cancer is a disease that largely affects the older population and young people fall outside of the referral guidelines, which may to some extent, explain why they experience referral delays (8, 9). Researchers at Imperial College London linked data from the Cancer Registry and the Clinical Practice Research Datalink database and found that young patients (<50 years old) were more likely to present with abdominal pain, be diagnosed with colorectal cancer at a later stage, and via an emergency, compared with all other age groups. The fact that younger people are largely diagnosed at emergency implies that there were missed opportunities in primary care(8).

The NHS in England currently offers cervical screening to women ages 25-64. Researchers investigating delays in diagnosis of young females with symptomatic cervical cancer found that 28% delayed presenting with symptoms and delays were more common amongst those younger than 25 years of age(10). Many participants in the study reported that they did not recognise the symptoms of cervical cancer such as vaginal discharge, postcoital (after sexual intercourse) bleeding and intermenstrual bleeding, which are common amongst women without malignancy. The study also identified delays in diagnosis but the researchers were unable to find conclusive evidence to explain why(10).

Many older women are not aware of the increased risk of cancer as they age and generally have poor knowledge of non-lump symptoms (1). Older women’s knowledge of the symptoms and risk of breast cancer are poorer than that of the
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general female population(11). A significant proportion report that they never feel their breasts even though a breast symptom in an older woman is highly indicative of cancer(1, 11). The evidence suggests that lack of awareness is the probable cause of delays in presentation and consequently diagnosis leading to poorer survival outcomes for older women.

Ethnicity

A UK study assessing the relationship between ethnicity, social deprivation and late presentation of colorectal cancer found that patients of Black ethnicity were more likely to present with advanced tumours at the time of diagnosis(5). It is commonly believed that this is due to socioeconomic disparity, however, this study found that Black patients were at increased risk of late cancer presentation irrespective of affluence or deprivation. The authors speculate that patient factors such as cultural attitudes, beliefs and embarrassment, as well as limited access to healthcare may contribute to delays in Black people presenting with their symptoms. Other factors that may contribute to delays in diagnosis include primary care physicians’ perceptions of their patients’ need for referral and their referral behaviour.

A small study of cancer patients in West Yorkshire, UK, found that South Asian women were more likely to present late with breast cancer symptoms – 91% of the research cohort had advanced disease(12). The study revealed that even though most patients were eligible for screening only a small proportion engaged with the national screening programme. A much larger study in Canada involving 41,296 women also found that breast cancer was diagnosed at a later stage amongst South Asian women but that Chinese women were diagnosed at an earlier stage, highlighting that the stage of cancer at diagnosis can vary between ethnic groups(13). The disparity between the two ethnic groups appears to be explained by the degree of engagement in health promotion initiatives and screening programmes.

A systematic review assessing the inequalities in the time of cancer diagnosis, identified three main intervals of cancer where outcome affecting delays can occur, the patient interval (recognition of symptoms), the primary care interval (presentation of symptoms) the diagnostic interval (diagnosis and treatment). The review found insufficient good quality evidence ‘to confirm or refute ethnic inequalities in diagnostic intervals of cancer’, p197(14).

Gender

Women are at increased risk of emergency presentation for bladder, brain, rectal, liver, stomach, colon and lung cancer, whilst men are at increased risk of emergency admission for oral/ oropharyngeal cancer, lymphomas and melanoma(7). The
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Symptoms for the latter are relatively clear-cut leading to the hypothesis that emergency presentation is likely to be due to lower rates of body awareness and reduced ability to appraise and seek help for obvious symptoms. In contrast, for women, emergency presentation for bladder cancer is likely to be due to general practitioners not immediately suspecting cancer resulting in long intervals between presentation and diagnosis.

A systematic review investigating bladder cancer survival in women cites studies showing that women frequently do not appreciate the significance of symptoms such as haematuria (blood in urine) resulting in delays in presentation(15). The review also found differences in referral patterns between genders with women needing to present symptoms more frequently in primary care (more than 3 pre-referral appointments) before being referred to secondary care. Women are often treated for other conditions such as urinary tract infections (UTIs) before a diagnosis of bladder cancer. ‘Having a diagnosis of UTI was found to be the most significant independent predictor of delay to bladder cancer diagnosis, approximately doubling the chance of a delay beyond 6 months’, p375.

Elsewhere in the literature some authors argue that comparatively poorer survival outcomes for women with bladder cancer are not explained by delays in presentation and diagnosis alone – ‘even after diagnosis and following definitive treatment women still suffer worse outcomes than men’, p25(16, 17). A review of 5377 new cases of bladder cancer in Sydney, Australia found no difference in the proportion of patients presenting at different stages between genders and yet there was a gender disparity in disease specific survival(16). The hypothesis is that biological factors also have an important role to play in survival outcomes(16, 17).

**Socioeconomic status**

The association between deprivation and late presentation of cancer symptoms and late stage cancer diagnosis is well recognised in the literature(18-21).

Pooled analysis of 18 international case control studies with an overall sample size of 10,601 women diagnosed with epithelial ovarian cancer showed that lower levels of education was associated with late stage cancer at diagnosis(20). The explanation for this is likely to be the interplay between a range of factors including, patient awareness of symptoms, patient access to healthcare and regular check-ups, referral to specialist care and comorbidities. It is hypothesised that highly educated women are more aware of, and able to, recognise cancer symptoms and they also respond more promptly to those symptoms(20).

Incidence of melanoma is increasing amongst higher socioeconomic status (SES) groups whilst lower SES groups are more likely to be diagnosed with late stage disease and have higher mortality rates(18, 22). A systematic review assessing the
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influence of lifestyle factors on melanoma found that poverty was associated with an increased risk of late stage melanoma presentation even when adjusted for age, sex, race and rural gradient(18). The findings of a similar study looking at the relationship between SES and melanoma in Northern Europe suggest that this phenomenon is due to higher SES groups being more knowledgeable about symptoms and their readiness to consult physicians and dermatologists about marks and moles(22).

There is increasing evidence of an association between deprivation and colorectal cancer(5, 23-26). The evidence suggests that deprivation is an independent predictor of late presentation(5). One large study involving 17,348 patients found that the most socially deprived group (quintile 5) were 1.26 times more likely to be diagnosed with stage IV tumours than the most affluent group(5). Similarly a retrospective cohort study of a population in North Wales, UK also found that there was significantly higher rates of late stage presentation in areas of lower SES, even though there was no difference in incidence(21). Like with other cancers the reasons for late presentation of colorectal cancer are not obvious, but the authors hypothesise that there are complex interactions between a variety of factors including poor participation in screening programmes and lack of education and knowledge about the disease process(5).

Discussion

It is clear from the evidence that a range of population groups are affected by inequalities in cancer presentation and diagnosis and that the reasons for this are multifaceted(5, 20). Despite the variety and complexity of the reasons however, lack of symptom recognition and knowledge stands out as the leading cause of delayed presentation and late stage cancer diagnosis, suggesting that campaigns to encourage early presentation should not only address barriers such as embarrassment and healthcare access, but they should also prioritise raising awareness and increasing knowledge of cancer symptoms(2, 10, 15).
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**Example search strategy**

**Ovid Medline (search undertaken by Lois Woods)**

1. exp "NEOPLASMS/"
2. ((late or later or late-stage or delay* or emergency) adj3 present*).ti.
3. ((late or later or late-stage or delay*) adj3 diagnos*).ti.
4. Delayed Diagnosis/
5. 2 or 3 or 4
6. 1 and 5
7. exp *PERSONS/
8. exp *sociological factors/
9. exp *Population Characteristics/
10. 7 or 8 or 9
11. 6 and 10
12. exp "Patient Acceptance of Health Care"/
13. Health Knowledge, Attitudes, Practice/
14. exp Health Education/
17. ("health promotion" or campaign or "patient education" or "health education").tw.
19. Symptom Assessment/
20. Diagnostic Self Evaluation/
21. ((symptom or symptoms) adj4 (understand* or assess* or self-assess* or evaluat* or apprais*)).tw.
22. ("patient delay" or "patient factor" or "patient interval").tw.
23. (barrier* or prevent*) adj2 "early presentation".tw.
24. or/12-23
25. 6 and 24
26. 11 or 25
27. disease-free survival/
28. "positive clinical outcome".tw.
29. "Early Detection of Cancer"/
30. 27 or 28 or 29
31. (present* adj2 (early or late or later or late-stage or delay*)).tw.
32. Time Factors/
33. 1 and 30 and 31 and 32
34. (children or child).tw.
35. adolescent/ or exp child/ or exp infant/

**Inclusion/exclusion criteria**

**Ovid Medline cont.**

37. 34 or 35 or 36
38. 11 or 25 or 33
39. 38 not 37
40. limit 39 to (english language and yr="2008 -Current")

**Inclusion criteria**

- delayed cancer presentation
- late stage cancer diagnosis
- women, men, ethnic minorities, young people, older people
- UK, Australia, Canada, United States, Europe

**Exclusion criteria**

- countries other than those listed above
- cancer per se
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