The Incidence and Survival of Kaposi Sarcoma Using The National Cancer Registry Data

Catarina Quaresma  Dermatology Specialty Trainee St3, Royal Devon University Healthcare NHS Foundation Trust
Agnieszka Lapin  Dermatology Senior Clinical Fellow, Norfolk and Norwich University Hospitals NHS Foundation Trust
Sally Vernon  Get Data Out Programme, National Disease Registration Service
Agnieszka Tan  Consultant in Genitourinary and HIV Medicine, Cambridgeshire Community Services NHS Trust
Zoe Venables  Clinical Associate Professor and Consultant Dermatologist, Norfolk & Norwich University Hospitals NHS Foundation Trust
Kaposi sarcoma

• Angioproliferative tumour, most commonly presenting in the skin with purple patches, plaques or nodules. Mucosal and internal involvement is seen less commonly.

• Described in 1872 by Mortiz Kaposi, who defined the classic type of Kaposi sarcoma (KS) in several elderly men of European descent as a disease of an indolent course.¹
Kaposi sarcoma - pathogenesis

Infection with human herpes virus 8 (HHV-8) is necessary for the disease development, but insufficient on its own.\(^2\)

Co-existing immunosuppression, as seen in AIDS, is required for the viral oncogenesis.\(^2\)

HHV-8 immunostain provides an accurate diagnosis, distinguishing KS from other vascular tumours.
HHV-8 prevalence

- **High**
  - >90% in adults
  - Sub-Saharan Africa

- **Intermediate**
  - 20-30%
  - Mediterranean

- **Low**
  - <10%
  - Northern Europe, Asia, USA

Kaposi Sarcoma Incidence

The onset of AIDS pandemic

Zidovudine FDA approval

Introduction of HAART
Kaposi Sarcoma incidence in England

- Only one epidemiological study in England and Wales to date.  
- 68 cases reported between 1971 and 1980
- Incidence rate of 0.01 per 100,000 person-years.
- Male to female ratio was equal to 1.
- Migrants from Eastern Europe, Mediterranean, Africa and Middle East were at higher risk of developing KS in comparison to people born in the UK.
Get Data Out Programme

- National data from the National Disease Registration Service (NDRS) is available for 2013 – 2020 via the Get Data Out Programme.
- Only the annual figures are reported, no further division of patient groups.
- Cancer registration data is gathered for tumours coded to ICD-10 C46 (WHO) from pathology laboratories, MDTs treating patients with cancer, and death certifications.
Kaposi Sarcoma incidence rate in England

Incidence Rate Per 100,000 person-years

England: 0.156
USA: 0.331

Data source:
For UK: Get Data Out Programme
For USA: Surveillance, Epidemiology, and End Results Program (SEER)

Data source: GLOBOCAN 2020; International Agency for Research on Cancer
Routes to diagnosis

- **Emergency Presentation**: 11%
- **Outpatient referral**: 25%
- **Non-2WW Route Referral**: 37%
- **GP referral**: 10%
- **Elective Inpatient**: 1%
- **Route Unknown or Unclassified**: 16%

1 case out of 812 identified on death certificate

Kaposi sarcoma – net survival

Cancer data registry. Get data out programme, Kaposi sarcoma. Get data out
https://www.cancerdata.nhs.uk/getdataout/kaposisarcoma
Conclusion

1. First nationally reported epidemiological data on Kaposi sarcoma since the 1980s.

2. More data on patients demographics and Kaposi sarcoma subtypes are needed.

3. 11% of cases still presented as an emergency.

4. The true incidence of Kaposi sarcoma is likely underreported as patients could be managed outside of a cancer setting – e.g. patients living with HIV managed in GUM/HIV clinics.
   - No histological confirmation of KS
   - KS diagnosis absent on the death certificate

www.cancerdata.nhs.uk/getdataout
References


