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Title: Diagnostic delay in AYA sarcoma patients - does it exist and what are the contributing factors

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Introduction:

Sarcoma is a stream of cancer involving connective tissue and non-epithelial tissue. These cancers lie under the broad subcategories of bone sarcoma and soft-tissue sarcoma.

Adolescents and young adults (AYAs) are at risk of a delayed diagnosis of cancer and presenting with advanced or metastatic disease. Late presentation of cancer correlates with a worse prognosis and increased chance of mortality. Previous research has shown that the majority of the delay is due to the greater time taken for a young patient to seek initial medical attention. This could be due to a myriad of underlying factors, both psycho-social reasons as well as problems within the healthcare system.

Aim:

To determine the time from the first recognized symptom to the date of diagnosis and first treatment for 20 sarcoma patients from each of the paediatric, AYA, and adult patient groups. To also identify any additional factors related to the individual or the disease that may influence the time to diagnosis.

Impact:

This study has found a difference in the diagnostic intervals between AYA, paediatrics and adults. It will lead to further questions towards identifying the underlying barriers and factors for a delayed diagnosis. Recognizing the common delay factors may allow the development of improved access to specialist treatment for AYAs.

Method:

Clinical documents from each patient's medical file were analyzed to determine the total symptom interval and other factors potentially contributing to the time delay. The total symptom interval was divided into three main intervals:

- *Patient delay:* from when symptoms are first noticed to the first presentation to a health care provider.
- *Referral delay:* from the first presentation to being referred to a specialist with suspicion of cancer.
- *Specialist delay:* from specialist referral to first treatment.

Additional variables recorded included gender, histology of the cancer, staging, primary tumour location, initial signs/symptoms and the first health care professional contacted. Age groups were classified by age at diagnosis, into paediatrics (0-14 years), AYA (15-24 years) and adults (25+ years). All patients resided in the South Island and were treated in Christchurch or Dunedin. Data

from 65 patients were recorded: 23 paediatrics, 19 AYA and 23 adults. The numbers weren't exactly 20 due to the availability of data and exclusions were made.

Results:

This retrospective study showed a relationship between the symptom interval and the patient's age. The median symptom intervals for paediatrics, AYA and adults were 70, 122 and 126 days respectively. Although adults and AYA had a similar total symptom interval, they showed differing component intervals. AYA had a median patient delay of 84 days, a marked increase compared to paediatrics (24.5 days) and adults (60 days). AYA also had a slightly greater median referral delay of 22.5 days compared to paediatrics (8.5 days) and adults (19 days). Adults showed the longest specialist delay (42 days) whereas paediatrics and AYA had a shorter time from referral to start of treatment.

The median symptom intervals were also compared by other variables including patient and disease related factors. The medians were balanced between male and female. Bone sarcoma tended to have a longer interval compared to soft tissue sarcoma. Stage 1 diseases had the longest median interval. The primary tumour location with the longest median interval was the thigh, buttock and groin category, followed by the extremities. Presenting with a specific symptom associated with the tumour tended to have the shortest symptom interval. An initial presentation to a GP was associated with a greater interval, while presentation to an ED doctor correlated with a shorter interval.

Conclusion:

Some particular psychosocial factors regarding AYA patients may explain the longer patient delay observed. Adolescents may be less aware and less likely to self-report cancer-related symptoms and seek medical attention. The increased referral interval in AYA could be attributed to problems within the health care system, such as inefficient, slow referral to the appropriate specialist by the GP. Lack of awareness among GPs of symptoms of rare cancers may also explain a delay in referral. Adults showed to have the longest total interval, however this may be due to the prolonged specialist delay or other confounding factors. For example, adults had the greatest number of initial presentations to the GP, which correlated with a longer interval.

There were limitations of this study. The population was small and confined to the South Island. To increase generalizability, the sample size would need to be larger, perhaps a nationwide pool. Results may be influenced by recall bias due to patients recalling symptoms and perceived time intervals from when they first began. The tumour stream was confined to sarcoma to maximise comparability. However, the subtypes of disease varied between age groups due to the differing biological developmental stages. Bone sarcoma was more common in AYA, whereas paediatrics and adults had a greater incidence of soft tissue sarcoma.