

European Association of Urology – press release

People with learning difficulties 4 times more likely to die of testicular cancer

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People with learning difficulties are 4 times more likely to die of testicular cancer than the general population. This is the first work relating cancer deaths to learning difficulties, with researchers now testing if this finding applies to all cancers.

The UK study, which is presented at the European Association of Urology conference in London, has found that testicular cancer sufferers who also have learning disabilities (LD) have a 1 in 10 chance of dying from the cancer, as opposed to a 1 in 36 chance in the general population. As this is the first major study to look at cancer survival rates in people with learning difficulties, the authors don't yet know if this increased mortality rate applies to all cancers or just to testicular cancer.

Around one and a half million people in the UK are classified as having learning difficulties. Research has found that males with intellectual disabilities die on average 13 years earlier than the general population. In females the situation is even worse, women with intellectual difficulties die on average 20 years earlier. Most of these deaths are believed to be due to cardiovascular disease, but now a group of UK scientists and clinicians have looked at the testicular cancer incidence and how it relates to learning difficulties.

Using the NHS's Hospital Episode Statistics database, the team, based at the University of Birmingham identified 158,138 male patients with learning difficulties. Over a 14 year period from 2001 to 2015, they found that 331 had testicular cancer, and 32 died of cancer. In the general population 25,675 had testicular cancer with 713 cancer specific deaths, meaning that the rate of cancer deaths was significantly higher in people with learning difficulties.

The work's lead author Dr Mehran Afshar (St George's Hospital, London) said "We found that people with learning disabilities are not only more likely to develop testicular cancer, but are also far more likely to die from it than the general population. Testicular cancer is relatively rare, but if similar imbalances apply to all cancers, which we suspect to be the case, this would make excess cancer deaths associated with learning difficulties a significant public health issue. However, we don't yet have any statistics to confirm this. We are still processing the data on other cancers, such as prostate, breast and colorectal cancer".

"We propose that there might be several reasons which cause this disparity in survival, perhaps including the possibility that men with learning difficulties are not so good at self-examination, going to the doctor, and then following through with any treatment. It could also be that because consent is more difficult to obtain from these patients it affects the treatment they receive".

Although cure rates for testicular cancer are high, it is the 3rd leading cause of cancer death amongst men aged 18 to 50. Between 1979 and 2006 there was an 82% increase ** in incidence in Europe (although rates have been stable since). Several high-profile cases have raised the public visibility of testicular cancer in the recent years, the cyclist Lance Armstrong being the best known. Overall, cancers are less common in patients with learning difficulties, although this is changing as LD patients are generally living longer.

Commenting, Professor Jens Sønksen (University of Copenhagen) of the EAU Scientific Congress Committee said;

“Recently we have seen an increased focus on inequality in health care as it appears that people of different backgrounds receive health care of different quality.

This study is important because it identifies a vulnerable group of patients at increased risk of cancer mortality. As health care professionals we will need to develop methods to provide better health care focused specifically on people with intellectual disabilities”.

ENDS

*UK testicular cancer incidence and mortality, <http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/testicular-cancer>

**<http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/testicular-cancer/incidence#heading-Two>

Notes for Editors

PLEASE MENTION THE EUROPEAN ASSOCIATION OF UROLOGY CONGRESS IN ANY STORY RESULTING FROM THIS PRESS RELEASE

The 32nd European Association of Urology conference takes place in London from 24th to 28th March. This is the largest and most important urology congress in Europe, with up to 13,000 expected to attend. Conference website <http://eau17.uroweb.org/>

How has this work been reviewed? This work has not gone through a journal peer-review process. This work is amongst the top-rated 150 abstracts (out of 1171 accepted from around 5000 submissions) from the EAU congress. It was reviewed for suitability and accuracy by members of the EAU communications group at more than one stage in development, and subsequently reviewed by a specialist in the field on behalf of the EAU.

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Title: Testicular cancer in patients with learning disabilities in England from 2001-2015: A national cohort study

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Introduction & Objectives There are 1.5 million people in the UK with learning disabilities (LD). This vulnerable group of society derives less benefit from population based education programs about health. They are particularly prone to under-enrolment into cancer screening programs and may lack the knowledge or ability to perform self-examination. We aimed to identify patients with LD in England, and assess the characteristics and survival with testicular cancer in comparison to the general population.

Material & Methods Patient records were identified and data was collected from the Hospital Episode Statistics database. All patients resident in England having a diagnosis of 'mental retardation', or of 'developmental disorder of scholastic skills', or attending either as an outpatient or an inpatient under the speciality of 'learning disabilities', between 1st of April 2001 to 30th June 2015 were included in our analysis. Kaplan meier tests were performed for survival analysis, and log rank test was used to assess survival difference between demographic groups in the LD and non-LD patients.

Results 278,314 patient records were extracted and identified as having LD. Of 158,138 male patients 331 had testicular cancer, and 32 died of cancer. In the general population 25,675 had testicular cancer with 713 cancer specific deaths. LD

patients had a poorer prognosis, with 10 year cancer specific survival being 88.4% (95% CI: 84.5%-92.4%) in the LD group versus 96.8% (95% CI: 96.6%-97.1%) in the non-LD group. The LD group had more co-morbidities, and were of poorer socio-economic background, although this did not significantly impact survival in our analysis.

Conclusions Education regarding self-examination for testicular cancer must be provided in a format suitable to those with moderate to severe LD, in the fashion that information is tailored towards those patients who speak different languages, or who have different cultural needs. Carers for male patients with LD should be informed about testicular examination and symptoms of disease, so that they are empowered to attend to sinister signs or symptoms.

Funding: there was no external funding for this research.