

Anal cancer is on the rise; it's a shame ...

Stephen Leppard

'The diagnosis is anal cancer,' I hear the oncologist say firmly and formally. As the words leave her mouth and approach me, however, I am whisked away to a subterranean cavern, cool and silent, where the doctor's voice barely penetrates, and the outside world seems distant and unreal: am I dreaming?

I already know the fact of the diagnosis: a medical degree and 25 years working in the field means that as a male, 49 years of age, with perirectal bleeding and a firm irregular mass that I have just discovered inside my anal canal, there is no doubt that I have developed anal cancer. It is hearing the words spoken aloud for the first time that throws me so abruptly off balance.

My body tenses and withdraws subtly away from the doctor and her strangely offensive words. A barrage of thoughts arise, crash chaotically into one another, jostling for supremacy. The triumphant thought is not one about how I acquired the disease; it is not a thought about the various medical treatments available; it is not the question concerning whether the cancer is curable or not; it is not even a thought about death – something that has just become significantly more tangible and imminent than it was only moments before. No, the victorious thought on hearing the diagnosis is my reaction to the type of cancer I have acquired: anal cancer. Oh no, anything but that ...

Cancer, 'the emperor of all maladies',¹ as Siddhartha Mukherjee evocatively names it in his Pulitzer Prize-winning book, is the supreme challenge of the current era for the medical profession. Incidence and mortality rates for many cancers continue to rise despite daily breakthroughs in the

understanding of pathogenesis, and development of new treatments.

The incidence of anal cancer, while low when compared with the big names – prostate, breast, bowel, lung – is most definitely on the rise. In Australia, the incidence of anal cancer increased by 50% between 1982 and 2005.² The annual rate of increase was two-fold higher in men than in women.

Table 1 shows that in Australia, for gay and bisexual men who are human immunodeficiency virus (HIV)-positive, the incidence of anal cancer (100+/100,000) is higher than that of bowel cancer (73/100,000)³ and close to that of prostate cancer (170/100,000);⁴ this is a noteworthy statistic for medical professionals working with this demographic.

I received my diagnosis of stage IIIB anal cancer in April 2013. For the year following the diagnosis, I was unable to speak the words 'anal cancer' out loud. The emotion fueling this reluctance was clearly shame. I told people that I had bowel cancer, although medical professionals quickly saw through this veneer of subterfuge when the treatment I had undergone was revealed.

I received the standard chemo-radiation regime as initial treatment, but just nine months following its completion, I developed a local recurrence, and abdomino-perineal resection was necessary. Following this surgery, with the undeniable reality of a permanent colostomy to manage on a daily basis, any energy that was being put into holding onto shame around the diagnosis quickly evaporated. I accepted that my body was affected by anal cancer and I started to talk about it openly. The most common response to these discussions was the virtual absence of knowledge about, and often of the very existence of, anal cancer. The issue of the stigma around the diagnosis of anal cancer, and the almost universal feeling of shame that I encounter when talking to people about it, has become the most interesting aspect of this journey for me.

A consequence of the shame and stigma that is associated with the anus for many people is that symptoms of diseases of the anus tend to be ignored. In my own personal experience, medical professionals tend not to get involved in anal issues unless absolutely required to do so, and actual inspection of the anus is kept to a minimum.

Table 1. Anal cancer incidence in population subgroups^{2,6}

Population	Incidence (per 100,000)
General population	1–2
Women with previous anogenital HPV disease	10
Organ transplant recipients and immunosuppressed	10
HIV-negative gay and bisexual men	10+
HIV-positive heterosexual men and women	20+
HIV-positive gay and bisexual men	100+

To alleviate morbidity and mortality associated with anal cancer, increased knowledge, awareness and acceptance of the disease, particularly among high-risk communities and, importantly, among healthcare professionals, is needed. Being given permission to speak openly, free of shame, about the anus and its associated issues is the start. My role, and the point of this article, is to bring my personal story into the light, to acknowledge that shame and stigma exist, and to demonstrate that it can be transcended.

On a practical level, the study of the prevention of anal cancer (SPANC)⁵ is currently underway at The Kirby Institute for infection and immunity in society at the University of New South Wales. The goal of the study is to determine the best recommendations for screening for anal cancer in the high-risk population of gay and bisexual men. The study concludes in 2018, although interim results and recommendations may be available sooner.

Anal cancer is almost exclusively caused by infection with high-risk types of the human papillomavirus (HPV), types 16 and 18.⁶ In decades to come, HPV vaccination will lead to reductions in the incidence of anal cancer among men and women, but other interventions are needed until then.

Healthcare professionals should be aware of patient groups that are at increased risk of anal cancer – HIV-positive men and women, gay and bisexual men, women with previous anogenital HPV, organ transplant recipients and other patients on long-term immunosuppression therapy⁷ – and the possibility of anal cancer should come to mind during consultations with these patients, particularly if symptoms of anal disease are present.

Resources

- A training video for conducting digital ano-rectal examination (DARE) produced by the Melbourne Sexual Health Centre, www.anal.org.au/clinician/tutorials/AnalExam.htm
- Information regarding anal cancer and associated diagnostic techniques on the 'Seventh Planet' YouTube videos, www.youtube.com/user/AnalNeoplasia/feed?activity_view=1
- An Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (ASHM) webinar review of anal cancer and HIV, and the potential value of DARE, <http://vimeo.com/ashm/live/video/109082973>
- The Farrah Fawcett Foundation is an international group funding research into anal cancer as well as other HPV-related cancers, www.thefarahfawcettfoundation.org
- The International Anal Neoplasia Society (IANS) is dedicated to increasing knowledge of anal neoplasia, and hosts conferences and HRA workshops, www.ians.memberlodge.org
- The HPV and Anal Cancer Foundation aims to educate the public about anal cancer, address the stigma associated with the disease, and advocate for prevention and improved early screening methods, www.analcancerfoundation.org

Author

Stephen Leppard MBBS (UWA), FRANZCO, retired from medical practice in 2014, during treatment for recurrent anal cancer, after 25 years working in the medical field. Dr Leppard is now devoting his life to his passion of music, as well as becoming involved in advocacy work for people affected by anal cancer, Surry Hills, NSW. stevie@stevieleppard.com

Competing interests: None.

Provenance and peer review: Not commissioned, externally peer reviewed.

References

1. Mukherjee, S. The emperor of all maladies: A biography of cancer. New York: Simon & Schuster, 2010.
2. Jin F, Conway EL, Regan DG, et al. Trends in anal cancer in Australia, 1982–2005. *Vaccine* 2011;29(12):2322–27.
3. Cancer Australia. Bowel cancer statistics. Strawberry Hills, NSW: Cancer Australia, 2016. Available at <http://bowel-cancer.canceraustralia.gov.au/statistics> [Accessed 3 September 2015].
4. Cancer Australia. Prostate cancer statistics. Strawberry Hills, NSW: Cancer Australia 2016. [Accessed 3 September 2015].
5. Machalek DA, Grulich AE, Hillman RJ, et al. The study of the prevention of anal cancer (SPANC): Design and methods of a three-year prospective cohort study. *BMC Public Health* 2013;13:946.
6. Grulich AE, Poynten IM, Machalek DA, Fengyi J, Templeton DJ, Hillman RJ. The epidemiology of anal cancer. *Sex Health* 2012;9:504–08.
7. Ong J, Temple-Smith M, Chen M, et al. Why are we not screening for anal cancer routinely – HIV physicians' perspectives on anal cancer and its screening in HIV-positive men who have sex with men: A qualitative study. *BMC Public Health* 2015;15(1):67.

correspondence afp@racgp.org.au