

Bladder Cancer – Poor Understanding Jeopardises Care

On behalf of Action on Bladder Cancer (ABC), Dr Alison Birtle, Consultant Oncologist, Preston, tells us why a new charity, dedicated to bladder cancer, is needed to improve awareness and patient care.



Dr Alison Birtle,
Consultant Oncologist,
Preston.

Correspondence to:
Action on Bladder Cancer
(ABC), Barley Mow Centre,
10 Barley Mow Passage,
London W4 4PH, UK.
Email: abc@rightangleuk.com
Tel: 020 3142 6491.

Public Awareness and Burden of Disease

Bladder cancer: we don't mind talking about it, but over half of us have no idea what causes it, according to a general public survey [1] from the new charity, Action on Bladder Cancer (ABC) – www.actiononbladdercancer.org. The majority (88%) of 2,055 people invited to participate in the survey were willing to do so. Yet, over half of those surveyed had no idea what the most common cause of bladder cancer might be. A quarter (25%) also had no idea about the warning signs for the disease. These survey findings mark the launch of ABC as the only UK charity purely focused on improving the lives of people with bladder cancer. With over 10,000 people being diagnosed every year in the UK [2], ABC wants to ensure that bladder cancer is moved higher up the public health agenda to receive greater attention alongside prostate, breast and lung cancer.

Bladder cancer is the 4th most common cancer in men [2] and the 12th most common in women [2] with 10,300 new diagnoses per year in the UK. Approximately 75 to 85% present with non-muscle invasive (superficial) bladder cancer of whom 31% to 78% will recur and 0.8% to 45% will progress at five years [3]. Their natural history is dependent on six clinical and pathological factors: number of tumours, prior recurrence rate, size, carcinoma in situ (CIS), grade and stage. The first three are the best predictors of recurrence whereas the last three are the best predictors of progression [3]. It is quite rare in people under 40, but risk increases with age. Median age at diagnosis is 74 years, with 89% of patients aged 60 and older [4]. With an increasingly ageing population, the incidence of bladder cancer can only increase. The natural history of superficial bladder cancer is long, which is reflected in the 10-year relative survival rates for bladder cancer (Figure 1).

Current Management Options

The burden of ongoing, often life-long, surveillance by cystoscopy after initial diagnosis is therefore significant in terms of costs to the NHS and to the patient in terms on ongoing anxiety about relapse.

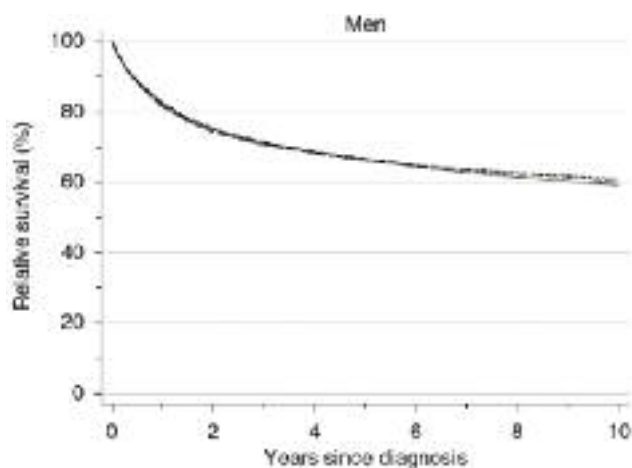


Figure 1: Relative survival (%) up to 10 years after diagnosis of bladder cancer, England & Wales, diagnosed during 1986-1999 and followed up to 2001. *British Journal of Cancer* 2008.

Yoshimura et al [5] found that there was global impairment of health related quality of life in 133 patients who had undergone multiple transurethral resections (TUR) of superficial bladder tumours compared to age-matched controls. Physical, social and role-emotional functioning all reached a nadir at the third TUR, then improved after the fourth resection. Less minimally invasive methods of surveillance may be perceived as more attractive, such as voided urine microsatellite analysis. However, the additional time incurred in waiting for laboratory based reporting rather than immediate visual inspection of the bladder produces additional distress in one in five patients [6].

Primary muscle invasive transitional cell carcinoma (TCC) carries significant risks of local progression and distant disease, with five-year survival figures as a group being poorer stage-for-stage than in many other tumour types: T2 60%, T3 45% and T4 15%. The optimum primary management for patients with localised bladder cancer remains controversial: the standard therapy in many countries is primary radical cystectomy, a procedure associated with significant morbidity and mortality rates. Selective bladder preservation using radical external beam radiotherapy in non-randomised studies seems to offer similar rates of overall survival [7], but a head-to-head comparison of radical cystectomy versus bladder preservation in the UK NCRI SPARE trial closed prematurely due to lower than anticipated recruitment rates.

Using platinum-based chemotherapy prior to either radical cystectomy or radical radiotherapy in muscle invasive bladder cancer can confer a 5% improvement in overall survival at five years, irrespective of the type of subsequent local treatment. This translates into a 14% reduction in the risk of death and a 9% improvement in disease-free survival [8]. Although not all patients are suitable for chemotherapy, these improvements in survival are comparable to those seen with the use of adjuvant chemotherapy in a number of other tumour types, such as breast and colorectal cancer.

Although the debate about optimum treatment of muscle invasive bladder cancer is ongoing, there is little doubt that raising public and professional awareness of bladder cancer will lead to earlier diagnosis and help improve survival rates.

About Action on Bladder Cancer (ABC)

ABC is working with healthcare professionals, patients, their carers and the general public to help improve the treatment and prevention rates of bladder cancer through raising awareness, education and research.

In the ABC survey, the most common cause of bladder cancer was thought to be drinking too much alcohol (18% of respondents). Only 5% said smoking and 1% using chemicals at work, although these in fact are the two main causes of bladder cancer. Industries involving dye, rubber, aluminium and leather are linked to an increased risk of bladder cancer.

The most common symptom of, or warning sign for, bladder cancer is blood in the urine, but only half of those surveyed mentioned this.

People living in Scotland, Yorkshire and East of England are more likely to understand the symptoms of bladder cancer. Those in

Series	Stages	N	Overall survival	
			5yr	10yr
Cystectomy				
USC (Stein et al 2001)	P2-P4a	633	48	32
VSKCC (Dalbagni et al 2001)	P2-P4a	181	38	27
Selective bladder preservation				
Erlangen (Rodel et al 2002)	cT2-4	326	45	29
MGH (Shipley et al 2001)	cT2-4a	190	54	36

Figure 2: Survival outcomes from contemporary series of selective bladder preservation or cystectomy, adapted from Shipley et al. (7).

Yorkshire and East Midlands are most likely to know of someone who has, or has had, bladder cancer. People in Wales tended to fare worst in terms of knowledge and understanding of symptoms.

Mr David Gillatt, Chair of ABC and Consultant Urologist in Bristol, says: "We don't expect everyone to be an expert, but such a huge lack of understanding can lead to people being mis-diagnosed and/or diagnosed at a later stage in the disease, which can narrow down the best treatment choices. Over the last 15-20 years, bladder cancer has been in the shadows. Greater public attention is urgently needed to improve understanding about the disease so that people know when and where to go for help. We also need to help people take steps to reduce their risk of getting the cancer in the first place, such as giving up smoking. In short, greater national funding needs to become a priority."

Along with awareness raising and scientific research, ABC intends to help improve the standards of care in the health service for bladder cancer patients. At the moment, patient care may be influenced by the local doctor's expertise and interest, as well as funding priorities within a specific Health Authority or Primary Care Trust. Standards need to be improved and care needs to be consistent throughout the UK.

"The profile of bladder cancer and, as a result, the care of patients can be significantly improved by asking the public and healthcare professionals and providers to become involved in our dedicated advocacy group, ABC (www.actiononbladdercancer.org) - we want to work together. We fully appreciate that other cancer and urology groups are already offering some valuable support, and where it makes sense to do so we are obviously very keen to combine our heavily focused efforts with them", concluded Mr Gillatt. ■



The official foundation of Action on Bladder Cancer is supported by educational grants from: Kyowa HAKKO Kirin UK Ltd, Alliance Pharma and GE Healthcare.

The Executive Committee for Action on Bladder Cancer (ABC)

Mr David Gillatt (Chair), Bristol
Mr Colin Bunce (Secretary), Hertfordshire
Mr Hugh Mostafid (Treasurer), Hampshire
Dr Alison Birtle, Lancashire
Mr Leyshon Griffiths, Leicester
Prof John Kelly, London
Mr Roger Kockelbergh, Leicester
Mrs Alison Palmer, Hertfordshire
Mr Raj Persad (Founding Chair), Bristol

References

1. GfK NOP Survey on bladder cancer for Action on Bladder Cancer, May 2010. [Survey Technical Details: GfK NOP interviewed 2,055 adults 16+ using face-to-face interviewing 13-15 May, 2010. Data has been weighted to bring it in line with national profiles. The survey is supported by an educational grant from Kyowa HAKKO Kirin UK Ltd.]
2. Cancer Research UK, Cancer Stats Key Facts, Bladder Cancer: go to http://info.cancerresearchuk.org/prod_consump/groups/cr_common/@nre/@sta/documents/generalcontent/crukmg_1000ast-2778.pdf
3. Sylvestre RJ, van der Meijden AP, Ossterlinck W, Witjes JA, Bouffieux C, Denis L, et al. *Predicting recurrence and progression in individual patients with stage TaT1 bladder cancer using EORTC risk tables: a combined analysis of 2596 patients from seven EORTC trials.* Eur Urol. 2006;49:466-75.
4. British Association of Urological Surgeons Cancer Registry data.
5. Yoshimura K et al. *Impact of superficial bladder cancer and transurethral resection on general health-related quality of life.* Urology 2005;65(2);290-4.
6. Van der Aa MN, Steyerberg EW, Sen EF, Zwarthoff EC, Kirkels WJ, van der Kwast TH, Essink-Bot ML. *Patients perceived burden of cystoscopic and urinary surveillance of bladder cancer: a randomised comparison BJUI 2008;101(9):1106-10.* Epub 2007 Sep 20.
7. Shipley et al. *Selective bladder preservation by combined modality protocol treatment: long-term outcomes of 190 patients with invasive bladder cancer.* Urology 2005;60:62-7.
8. Advanced Bladder Cancer (ABC) Meta-analysis Collaboration. *Adjuvant chemotherapy in invasive bladder cancer: a systematic review and meta-analysis of individual patient data* Eur Urol. 2005 Aug;48(2):189-199; discussion 199-201. Epub 2005 Apr 25.

Action on Bladder Cancer (ABC) Survey 2010

A picture of public understanding?

How common do people think it is?

- Whereas bladder cancer is the 4th most common cancer in men and the 12th in women, only 14% of people surveyed said they knew of someone with bladder cancer, but this figure increased with the age of the person questioned.
- People in Yorkshire, Humberside and the East Midlands were most likely to know someone who has or has had bladder cancer. This could be due to industrialised regions and a greater willingness to talk about the subject in these regions.
- One third of men (39%) and women (33%) thought that men are more likely to get bladder cancer. Only 18% of men thought that women would be most likely to get it and 28% of women thought that women would be most likely to get it.

Do people know the warning signs of bladder cancer?

- A quarter of respondents had no idea what might be a sign of bladder cancer and this was highest in the younger age groups. Only half of respondents understood the most common sign of bladder cancer to be blood in the urine.
- People living in Scotland, Yorkshire and the East of England are more likely to understand the symptoms of bladder cancer. Those in Yorkshire and East Midlands are most likely to know of someone who has or has had bladder cancer. Those people living in Wales tended to fare worst in terms of knowledge and understanding of symptoms.

What is the most common cause of bladder cancer?

- Over half of those surveyed had no idea what the most common cause of bladder cancer might be, and 18% thought it was drinking too much alcohol.
- Only 5% stated they thought smoking to be the most common cause, which is in fact the case, and only 1% said using chemicals at work, which is the second most common cause.

What was understood about treatments?

- One-third of people thought that chemotherapy was the most common treatment for bladder cancer, but one-third also had no idea. Twelve percent thought that removal of the cancer with surgery was an option.
- The survey revealed that general knowledge about treatments was poorest in the South East.

Where to go for help

- Of the respondents, 91% said that they thought the GP surgery would be the first port of call for information if someone suspected they may have bladder cancer. However, 12% did say that the internet would be an option for information.