Delay in the diagnosis of testicular tumours — changes over the past 18 years

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SUMMARY

Background: Delay in the diagnosis of testicular cancer is associated with greater morbidity and poorer prognosis. While the national agenda relates to reducing time to referral and diagnostic delay, delay in presentation has previously been recognised as a major cause of delay in the diagnosis of this patient group.

Aims: To evaluate changes in referral times and patient awareness among men with testicular cancer in Yorkshire over the past 18 years.

Design of study: Prospective cohort study. Comparison was made with a similar study in Yorkshire in 1985.

Setting: Leeds Cancer Centre Testicular Germ Cell Outpatient Clinic.

Method: Three hundred and thirty-one men, newly diagnosed with testicular cancer between August 1998 and October 2002, were asked to complete a questionnaire. The time taken from when the patient first noticed symptoms to their first visit to their general practitioner (GP), from their first GP visit to their first hospital visit, and from their first hospital visit to orchidectomy were recorded. We also asked patients about the treatment they were offered at their first GP visit.

Results: Questionnaires were completed by 180 (54%) men. The median time that men took between when they first noticed symptoms and first visited their GP has decreased compared with 1985 (5 versus 2 weeks, respectively). No improvement was observed in referral times (mean = 3.55 versus 4.8 weeks). Ninety-one per cent of responders had heard of testicular cancer prior to diagnosis.

Conclusion: Patient performance has improved over the past 18 years. The data lends support to the effectiveness of national health education initiatives aimed at increasing public awareness and self-examination. GPs performed well in this study, assessing and referring men appropriately and urgently into secondary care.

Keywords: consultation and referral; delay; diagnosis; patient education; testicular cancer.

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Submitted: 18 November 2003; Editor's response: 18 March 2004; final acceptance: 25 May 2004.

©British Journal of General Practice, 2004, **54**, 595-597.

Introduction

TESTICULAR cancer is the most common malignancy in men aged between 20 and 34 years living in the United Kingdom (UK). There are around 1900 new cases diagnosed each year and the incidence is increasing.¹ These tumours are characterised both by their rapid growth and sensitivity to chemotherapy or radiotherapy, depending on the histological subtype. The prognosis is excellent for the majority of patients, with a greater than 95% cure rate in limited stage disease. However, in men presenting with metastatic disease out with the lymphatic system or the lungs, although cure is still achievable, this is only possible in 50–70% of patients.¹

Delays in diagnosis affect the stage of disease at presentation and therefore the prognosis.^{2,3} To address this, current guidelines state that all patients suspected of having testicular cancer should be seen urgently (within 2 weeks) by a specialist.4 However, delays in presentation have been shown to be more of a problem than delays in referral.^{5,6} In 1985, Jones and Appleyard reported the results of a retrospective audit, which showed that most patients in Yorkshire were referred urgently for further investigation and management by their general practitioner (GP), and that the principal delay in diagnosis was attributable to the patient.⁵ Men's knowledge of testicular cancer has been shown in the past to be poor.^{7,8} Eight years ago, the UK Department of Health launched a campaign to increase awareness and encourage testicular self-examination among young men.

Within Yorkshire, a single clinical team within the Leeds Cancer Centre manages all cases of testicular cancer following the referral of patients from their local hospitals. We conducted a prospective study in order to discover whether improvements, in terms of patient delay and referral times, have occurred since the previous audit in Yorkshire 18 years ago.

Method

Following approval from Leeds (West) Research Ethics Committee, every newly diagnosed patient who attended the Leeds Cancer Centre Germ Cell Tumour Clinic between August 1998 and October 2002 was invited to participate in a survey. Patients were asked to complete a questionnaire on the day of their first attendance, or to take it away and return it completed at the time of their next outpatient visit. We asked the men to identify as accurately as possible, the dates when they noticed their first symptom(s), when they first sought medical help, when they were first seen in hospital, and the date of orchidectomy. We also asked them what treatment they were offered at their first GP visit, and sought information

HOW THIS FITS IN

What do we know?

Delays in the diagnosis and treatment of testicular tumours have a negative impact on patient survival. Delays in presentation are a greater problem than delays in referral. The public's awareness and knowledge of testicular cancer is poor. Health education programmes have attempted to address this.

What does this paper add?

Until now, the impact of such initiatives on men's behaviour has not been assessed. Over the past 15–20 years the delay by young men in seeking medical attention has reduced. Health education programmes appear to have been successful in increasing men's awareness of testicular cancer.

regarding their pre-existing knowledge of testicular cancer. We have compared the findings of this prospective study with the results of the retrospective audit reported by Jones and Appleyard in 1985. The data was collected in exactly the same way, except that in the 1985 study, time to referral was recorded separately as first GP attendance to referral letter and referral letter to first hospital attendance. For this reason, and the fact that raw data from the previous study was no longer available, formal statistical comparison was not possible.

Results

Questionnaires were given to 331 patients, and 180 (54%) were returned.

The majority of men (95%) saw their GP at first presentation. The remainder were seen as follows: 2% in casualty, 1% in a private clinic, 1% incidentally in another hospital clinic, 0.5% by a prison doctor, and 0.5% in a work medical.

One hundred and sixty-three (91%) men had heard of testicular cancer prior to diagnosis. The most common source of information was from television programmes (53%) and newspapers and magazines (55%). Other important sources were health leaflets (20%), the radio (18%) and from various sources at work (15%).

The median time that patients took to seek medical attention from first noticing something wrong was 2.0 weeks. Sixteen per cent of men waited more than 2 months, 4%

waited more than 6 months, and one patient delayed his presentation for over 2 years.

The median time from the first GP visit to the first hospital appointment was 2.1 weeks; 48% of men were seen within 2 weeks. Eighty-six per cent of patients were seen within 2 months and 4% waited more than 6 months. The median time to orchidectomy from first hospital attendance was 0.7 weeks, but 8.4% of men waited more than 4 weeks for their operation (Table 1).

Of the men who attended their GP at first presentation, 69 (40%) were referred to hospital (+/- antibiotics/ultrasound scan) at their first visit. Of the remainder, 49 (29%) were sent for an ultrasound scan, 23 (14%) were prescribed antibiotics and 14 (8%) were sent for an ultrasound scan and given antibiotics. Eleven men (6%) were initially reassured and given no further appointment. Apart from being told there was 'nothing wrong', misdiagnoses within this group included hydrocoele, strain, and simply that the patient had 'one testicle bigger than the other'. Three men (2%) were given a later review and in two (1%) cases men were given painkillers/anti-inflammatories (Table 2).

Discussion

The national cancer agenda is focused on reducing the time taken to refer, diagnose, and treat patients. The National Institute for Clinical Excellence's *Improving outcomes in urological cancers* manual concentrates on ensuring that, once entered into specialist urological cancer care, outcomes are maximised by the selection of evidence-based treatments delivered by specialist teams. In the case of rapidly proliferating cancers, such as testicular germ cell tumours, the speed of referral into the specialist service is critical to the successful outcomes that we have come to expect for these tumours, since the bulk and degree of dissemination of disease at diagnosis is directly related to the chance of cure. 10

Our results show that there has been an improvement in the amount of time that men take between first developing symptoms and presenting to their GP — from a median of 5 weeks to 2 weeks (Table 1) — and the majority of patients (84%) presented within 2 months. This improvement may, at least in part, be explained by a greater awareness of testicular cancer among the population. Studies in the 1980s reported that over one-third of men had never heard of testicular cancer⁷ and over 85% of young men were unaware that they were at risk.^{7,8} In contrast, over 90% of

Table 1. Comparison between delay times in the current study and the previous audit in 1985.

Time in weeks	1985 Jones and Appleyard $(n = 121)$			2004 Vasudev <i>et al</i> ^a $(n = 180)$			
	Mean	Median	Range	Mean (95% CI)	Median	IQR	Range
First symptom to first medical advice	14.34	5.0	0–155	5.8 (4.0 to 7.8)	2.0	0.6–5.3	0–104
First general practice attendance to first hospital attendance	3.55	N/A ^b	0–42	4.8 (3.8 to 6.1)	2.1	0.9–5.6	0–40
First hospital attendance to orchidectomy	1.89	1.0	0–29	1.7 (1.2 to 2.2)	0.7	0.3–1.6	0–21

^aCurrent study. ^bOwing to differences in the way these data were collected. IQR = interquartile range; N/A = not applicable.

Table 2. Treatment offered at first general practice visit.

Treatment	Number of patients (%) $(n = 171)^a$
Hospital referral alone	51 (30)
Hospital referral and ultrasound scan	16 (9)
Hospital referral and antibiotics	2 (1)
Ultrasound scan	49 (29)
Antibiotics	23 (14)
Ultrasound scan and antibiotics	14 (8)
Painkillers/anti-inflammatories	2 (1)
Reassurance/no further appointment	11 (6)
Later review	3 (2)

^aExcludes those patients who did not see their GP at first presentation.

participants in this study had heard of testicular cancer before diagnosis.

Referral times do not appear to have changed. Overall, the median time taken from first GP visit to first hospital visit was 2.1 weeks. This means that just over half of the men were not seen within the recommended 2-week time frame.

Despite this, we believe that the GPs performed well in this study. Diagnosing testicular cancer can be extremely difficult,11 and patients with less-clear presentations will, therefore, justifiably take longer than 2 weeks to be referred.

An ultrasound scan (offered to 37% of non-referred patients at first presentation, with or without antibiotics), even if requested urgently (and chased up), will almost certainly push the time to referral beyond 2 weeks. A trial of antibiotics for suspected infection (offered alone to 14% of non-referred patients) is a reasonable first step, but doubtful epididymo-orchitis or orchitis that has not been resolved within 2 weeks must then be referred urgently.4 Together with the patients referred to a specialist at first visit, these treatments account for over 90% of cases. In only a small number of instances (6%) patients indicated that, at their initial consultation, they were reassured or given an alternative diagnosis.

It is clear that in general, GPs perform extremely well, assessing and referring patients appropriately and urgently. However, for a proportion of men, clinical examination may be misleading when no obvious mass is identifiable or when other pathology, such as a varicocoele, make assessment difficult. Perceived delay in diagnosis is the most common complaint from patients who are dissatisfied with the management of testicular tumours. National guidance is in place to improve outcomes for patients, and to guide and protect medical practitioners when the clinical picture is unclear.

The reduction in delay by young men seeking medical attention is encouraging. Over the past two decades greater emphasis has been placed on health education, particularly for men. Initiatives by various bodies including the Department of Health and cancer charities have helped to raise the profile of male cancers through use of the media, sport, and the work place. There is still scope for improvement so that early diagnosis and referral can occur, and a major challenge remains the targeting of individuals who still delay significantly.

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Acknowledgements

The authors are grateful to the patients who took time to complete this questionnaire, and to the nursing and medical staff who supported the study.