

# Qualitative study of men's perceptions of why treatment delays occur in the UK for those with testicular cancer

Alison Chapple, Sue Ziebland and Ann McPherson

## SUMMARY

**Background:** Many studies (but not all) have shown that for men with testicular cancer a longer treatment delay is associated with additional treatments, greater morbidity, and shorter survival.

**Aim:** This paper explores patients' perspectives on why treatment delays occur.

**Design:** Qualitative study using narrative interviews

**Setting:** Interviews in patient's homes throughout the United Kingdom (UK).

**Method:** Interviews with a maximum variation sample of 45 men with testicular cancer, recruited through general practitioners (GPs), urologists, support groups, and charities.

**Results:** Those who sought help relatively quickly responded to symptoms, had heard about testicular cancer in the media, had seen leaflets in GPs' surgeries, or knew others with this disease. Men delayed because they did not recognise signs and symptoms; feared appearing weak, a hypochondriac, or lacking in masculinity; recalled past illness or painful examinations; were embarrassed; feared the consequences of treatment; or lacked time to consult their doctors. Beliefs about symptoms and pessimistic associations with cancer also led to delay. Treatment delays also resulted from misdiagnosis or waiting lists.

**Conclusion:** Whether or not men should be taught to examine themselves routinely to check for testicular cancer is much debated. This study suggests that it is important that men are aware of the normal shape and feel of their testicles, and may benefit from information about signs and symptoms of testicular cancer and the excellent cure rate. Information, provided in surgeries where men feel welcome, might encourage men to seek help promptly when a problem arises. Our study also suggests that GPs may need to accept a low threshold for ultrasound investigation of testicular symptoms and that the ultrasound service needs to be improved. These measures may further reduce mortality and morbidity.

**Keywords:** testicular cancer; testis; delay; qualitative study.

## Introduction

TESTICULAR cancer accounts for about 1% of cancers in men, with a doubling of the incidence over the past 40 years.<sup>1</sup> The peak incidence occurs in men aged 25–35 years. Despite the rise in incidence, mortality from testicular cancer has fallen, and although certain groups of men have a poorer prognosis, the overall cure rate is now over 90%.<sup>2</sup> Many studies suggest that a long treatment delay shortens survival,<sup>3–5</sup> while others have not been able to demonstrate a relationship between delay in diagnosis and presenting stage, or a relationship between delay in diagnosis and outcome.<sup>6</sup> Indeed, the situation appears to be most complex.<sup>7</sup> However, it is generally accepted that early advice should be sought for any observed testicular changes and that early medical intervention is the best hope of catching early stage curable disease. Patients who delay may also need additional treatments and suffer associated morbidity.<sup>2</sup>

Thus we need to understand why long delays occur in certain groups of men. Most previous studies have used patients' medical records to examine why men with signs and symptoms of testicular cancer delay in seeking help.<sup>8</sup> Although such studies have provided some answers, qualitative research helps us to understand more about the context in which delays occur, it allows people the freedom to talk at length about what is salient for them, and provides richer explanations.<sup>9</sup> Case studies can also shed light on why delays occur in particular circumstances.<sup>10</sup> The authors of a recent qualitative study,<sup>11</sup> in which six men with testicular cancer were interviewed, concluded that their work should be seen as a pilot for further exploration and validation, and that future work on both patient and provider delay should not rely on hospital notes alone.

Many studies have shown that the presence of symptoms is not always sufficient for people to define themselves as sick,<sup>12</sup> or to seek medical care.<sup>13</sup> Various 'triggers' are known to encourage people to seek help,<sup>14</sup> and barriers, such as the fear of being labelled a hypochondriac, may prevent prompt consultation.<sup>15</sup> Moreover, numerous studies have looked at delay and factors influencing help-seeking behaviour for other types of cancer.<sup>16–19</sup> Oliveria *et al*,<sup>20</sup> for example, found that some people with malignant melanoma delayed in seeking help either because they were not aware of changes to their skin or because they were not knowledgeable about signs and symptoms of melanoma. While many studies have examined reasons for delay in help-seeking for symptoms of other cancers, relatively little is known about the illness behaviour of men with testicular cancer, or their perceptions of why delays occur once they present with symptoms.

A Chapple, BSc, MA, PhD, senior research fellow; A McPherson, FRCP, FRCGP, DCH, research lecturer, DIPEx, Department of Primary Health Care, University of Oxford, Headington. S Ziebland, BA, MSc, senior research fellow, Cancer Research UK General Practice Research Group and DIPEx, Department of Primary Health Care, University of Oxford, Headington.

Address for correspondence

Ann McPherson, DIPEx, Department of Primary Health Care, University of Oxford, Institute of Health Sciences, Old Road, Headington OX3 7LE. E-mail: ann.mcpherson@dphpc.ox.ac.uk

Submitted: 13 May 2003; Editor's response: 29 July 2003; final acceptance: 9 September 2003.

©British Journal of General Practice, 2003, 54, 25–32.

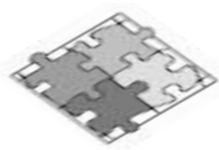
## HOW THIS FITS IN

*What do we know?*

Quantitative research has shown that men delay seeking medical help for testicular cancer because they do not recognise the significance of the symptoms, because they fear cancer and 'procrastinate'. However, little is known about the context in which delays occur, and there has been little qualitative work on the subject.

*What does this paper add?*

This study shows that there may be multiple complex reasons why men delay seeking help for testicular cancer, and we shed new light on why delay occurs. For example, men may delay because of childhood experience of illness or because of previous painful testicular examinations. It appears that treatment delays also occur because of misdiagnosis and waiting times for ultrasound investigations.



Men with testicular cancer who consult their general practitioners (GPs) promptly may still suffer from delays and misdiagnosis at various stages of their illness journey. A GP may see only one case of testicular cancer in a lifetime. Although in the United Kingdom (UK) anyone suspected of testicular cancer is now expected to be seen by a specialist within 2 weeks,<sup>21</sup> other causes of scrotal swelling and discomfort are far more common, and GPs may suggest an ultrasound before referral to a specialist. Appointments for such ultrasound examinations may take weeks or even months.<sup>22</sup> Thus early presentation of symptoms, suspicion of testicular cancer, prompt access to ultrasound investigations, and a short referral pathway are the limiting steps in treatment. This paper explores men's accounts of the factors that influenced their decision to visit a doctor, and men's perceptions of why misdiagnosis or administrative problems sometimes caused further delays in the context of the UK National Health Service.

## Method

### *The sample and the interviews*

Having obtained multiple research ethics committee approval, we interviewed 45 men, throughout the UK, who had been diagnosed with testicular cancer. Our aim was to conduct a qualitative research study of men's entire experience of testicular cancer, to contribute to the website, Personal Experiences of Health and Illness (DIPEX), [www.dipex.org](http://www.dipex.org). A maximum variation sample was chosen to include younger and older men from various social backgrounds, men diagnosed with seminoma or teratoma, and those who had been treated in different ways.<sup>23</sup> Men were recruited from all over the UK, though one man, a Canadian, was only temporarily staying in England. Most men were recruited through GPs, urologists, support groups, and charities. Three men were recruited via colleagues, and four men read about the website in various newspaper articles and then volunteered to take part. Sample characteristics are shown in Table 1. (For further details about participants see [www.dipex.org](http://www.dipex.org).)

Table 1. Characteristics of 45 men interviewed about their testicular cancer in 2001/2002.

Characteristic	No. of men
Age at interview (years)	
20–30	8
31–40	14
41–50	13
51–55	10
Ethnicity	
White British	43
Canadian	1
Former Czechoslovakia	1
Employment (includes those retired for medical reasons)	
Professional/higher managerial	20
Other non manual	14
Skilled manual	5
Unskilled manual	4
Students	2
Number of testicles involved	
Born with only one testicle, in which cancer developed	2
Cancer in both testicles	1
Cancer in one testicle, other one fibrosed and infected	1
Cancer in one testicle, other testicle healthy	41
Patient delay	
Long delay (3 month–2 years)	11
Short delay (weeks but less than 3 months)	14
Other reasons for delay (eg. misdiagnosis)	11

With informed consent, one of the authors, a medical sociologist, interviewed the men in their homes between August 2001 and February 2002. Men were asked to tell their story from when they first suspected that they had a problem. Open-ended narrative-based interviews, where respondents are asked to tell their story, allow respondents to highlight the issues that are most important to them. Among other things, we were interested in how all of the men talked about why and when they decided to consult their GP. Men were asked to explain in detail why any delays had occurred, and it is this aspect of men's stories that is reported in this paper. The interviews lasted 1–3 hours and were audiotaped.

## Analysis

The interviews were fully transcribed, and each transcript returned to the respondent to read. Seven men made minor revisions, none related to treatment delay. Having studied the transcripts the authors developed 'categories' or 'themes'.<sup>24</sup> Some of these were anticipated, but others, such as the category 'delay due to misdiagnosis', were developed from the data. Using the computer programme NUD\*IST,<sup>25</sup> sections of text from interviews were marked, removed and linked to sections of text from other interviews that covered similar issues or experiences. Then each category or theme was considered in the light of the context of the whole set of interviews.<sup>26,27</sup> The relevant NUD\*IST 'reports' and interpretation of some of the data were discussed. Inter-rater reliability scores were not developed as the interviews had very little structure. Such scores are not appropriate to data that has little or no pre-defined coding.<sup>28</sup>

## Results

The 45 men we interviewed were aged between 21 and 55 years. When interviewed, one man was still in the middle

of his treatment. Eleven others were diagnosed in the 2 years before the interview. Seventeen were diagnosed 2–5 years before the interview, and 16 were diagnosed more than 5 years before the interview took place. Men reported a wide range in the time taken to consult a GP with signs or symptoms (Table 1).

### *Those who sought help relatively quickly*

When telling their stories, some men mentioned factors that had influenced their decision to examine themselves carefully or factors that had influenced their decision to consult a doctor relatively quickly. Symptoms were important. In most cases the man had either found a lump or the testicle had been swollen or painful:

*'It was probably September 1998 and I was having a bath one evening, and I've always been brought up by my mum sort of to test myself, to test my testicles for testicular cancer. And I found this lump on my testicle, and I shot to my feet. I knew exactly what it was ... I'd read a fair bit about it as well, on TV and in magazines, so on the other side I wasn't that apprehensive about it because I knew it was something that was easily treated.'* (T44, aged 30 years, diagnosed 1998.)

Information leaflets found in doctors' surgeries appeared to influence some men:

*'It was in August 1998, well a little while before that, I'd been in the doctor's surgery for something minor and I picked up a leaflet on testicular cancer and how to test yourself you know, how to check yourself and everything. So I didn't think any more of it really. And then I was sitting in the bath one day and I just decided I'd check myself and I was feeling my testicles and I found one of them, I just found that when I pushed my finger along it there was a lump at the end, OK. So I was a bit concerned about that and so I decided I'd go to the doctor's the next day.'* (T33, aged 39 years, diagnosed 1998.)

The media also appeared to affect illness behaviour. Articles about testicular cancer found in magazines and newspapers were often mentioned, as the following two examples illustrate:

*'But anyway I was a little bit concerned as to what it [the lump] was, but put it out of my mind. And then strangely enough I was reading a magazine that I'd picked up at the airport on the way out and it was the FHM magazine and there was an article in there about one of the writers who'd thought he'd found a lump and went to the doctors. So after reading that I thought I'd better, better take another look, you know another feel around.'* (T10, aged 36 years, diagnosed 1994.)

*'It was 4 years ago last July I first found I had a lump. And I'd only been really looking for lumps for about 3 or 4 months before that because I read an article in the Daily Mail I think it was about that time. So I started looking*

*from then on every time I had a shower, after playing tennis or something like that. I used to examine myself all the time then.'* (T21, aged 53 years, diagnosed 1997.)

A radio programme may have affected one man's decisions to examine himself:

*'Er I guess it was last year, about in July 2001. I don't know why particularly I examined myself, I wasn't in the habit of doing regular examinations, I think there might have been some publicity on the radio at the time. Anyway I did check myself and found quite a difference between the two testicles. The one which had the cancer felt very firm over the entire surface of the testicle, it wasn't a small pea shaped, pea lump or anything like that, which had been suggested, and the other one felt normal, soft throughout.'* (T38, aged 42 years, diagnosed 2001.)

Knowledge of cancer in the family and a friend's experience of cancer made two men aware of the disease and encouraged self-examination:

*'It was probably about a year ago now but I was regularly checking myself anyway due to family history of mum and dad passing on with cancer. So since they passed on I was regularly checking myself anyway. Best time to check yourself was in the bath each evening. So I was checking myself one evening in the bath and noticed there was like a hard lump in one of my testicles.'* (T25, aged 28 years, diagnosed 2001.)

*'OK, in the summer of 2001, in July, I was doing regular self-checking, a friend of mine had had testicular cancer and had made me aware of the disease and so you know with no great regularity or system in mind I was checking myself.'* (T34, aged 33 years, diagnosed 2001.)

One man was a GP, so was well aware of the significance of his symptoms:

*'Right, well I was perfectly well until the end of December 1997 and the first thing I noticed was some discomfort in the left testicle, somewhat short of a pain but I felt that there was a lump there, I hadn't noticed it before and obviously with my background I was aware that this was of some significance. I went to see my GP the next day.'* (T05, aged 46 years, diagnosed 1997.)

### *Patient delay*

Some men delayed for weeks before consulting their GPs about symptoms, and others delayed for months. Our findings help to explain why relatively long delays occurred.

*Interpretation of symptoms.* Men with testicular cancer often delayed seeking help either because they were not in pain, or because there was no obvious lump. One man delayed for 2 years, mainly because he felt 'fit' and was pain free. It is interesting to note that he delayed in spite of hearing about testicular cancer on television:

*'I noticed that my testicles were of different sizes. I don't know whether they'd always been like that, or if I'd just suddenly noticed, but you know hearing things on the television and reading in the newspaper about potential problems in that area that started to concern me somewhat. I didn't actually do anything about it, I just was thinking about it and then I tried to push it to the back of my mind ... But as I was fairly fit and young, and it wasn't affecting me, I wasn't getting any pain, ... I didn't really feel that it was too urgent to get anything sorted out. So I basically just lived with it and kept monitoring the situation for a couple of years after that.'* (T07, aged 36 years, diagnosed 1998.)

This man finally decided to seek help when he moved house and was given a leaflet about testicular cancer as part of a 'welcome pack' when he registered with a new doctor.

Another man delayed seeking help for 3 months because, although his testicle was abnormally firm, there were no lumps and no pain:

*'My testicle was larger than it should be, very, very firm, it was like a rock, but no pain, no sensation, nothing. And I thought, well maybe it's just something that will go away on its own, so I just carried on with life.'* (T24, aged 50 years, diagnosed 1984.)

One man delayed for 18 months, partly because he had had other surgery in the scrotal area, which led to confusion, and partly because he thought the unaffected testicle was getting smaller, and so he did not realise that his affected testicle was getting so much bigger:

*'It started with the hardening of one of my testicles, the left, and it slowly got bigger. I'd had a lot of surgery in that area before, so I put it down to some sort of latter side effect from that. And I actually thought the unaffected side was getting smaller; that was my reasoning, until it got to such as size it became uncomfortable.'* (T09, aged 46 years, diagnosed 1999.)

Sports injuries and trauma were also confusing, and led men to misinterpret symptoms. For example, one man, who delayed seeking help for 3 months, blamed his dog's exuberance for the painless swelling:

*'I was convinced that it was Josh, the golden retriever, having pummelled me against the wall like he always used to do ... And I thought honestly that he'd knocked one of my testicles. You see it didn't hurt.'* (T37, aged 50 years, diagnosed 1991.)

A few men discovered that they had testicular cancer after it had spread elsewhere. For example, one man delayed seeking help partly because he thought the lump at the top of his leg was unimportant:

*'I happened to find a very small lump. Not actually on the testicles or anywhere in that area, it was at the top of the leg actually. I didn't do anything about it for about 2*

*3 months because I didn't know anything about cancer at all, I'd never really heard of it. I just happened to be at the doctors for something else and I happened to mention it to him and from there I went to see a specialist and had the biopsy and unfortunately it come back as cancer.'* (T39, aged 41 years, diagnosed 1996.)

**Masculine self-image.** It seems that some men delayed seeking help because of factors affecting masculine self-image. These included fear of appearing weak, fear of being seen as a hypochondriac, and fear of loss of masculinity. In the UK illness is often regarded as a form of weakness,<sup>29</sup> and men are not expected to appear weak or to express distress. A recent interview study of men with prostate cancer throughout the UK, found that men were reluctant to seek medical advice because, in their words, 'men don't cry'.<sup>30</sup> In our study of testicular cancer this was evident too. For example, comments made by one man (T09), who was confused about signs and symptoms (see above), suggest that he delayed for 18 months before seeking treatment, partly because he did not want to appear weak:

**Interviewer (I):** *'Why did you delay for so long?'*

**T09:** *'Er, well I've thought long and hard about that, and I wondered if deep down I knew there was a problem but I didn't like to face the fact, maybe. But it wasn't pain, it wasn't uncomfortable for a long time, and I think in general men don't want to know.'*

**I:** *'Why do you think men in particular?'*

**T09:** *'I'm not sure. I don't think they like to make a fuss, perhaps to be seen to be weak, caring for their bodies.'*

In the late 19th century and early 20th century, upper class 'delicate' women were often treated for hysteria and hypochondria.<sup>31</sup> Women were confined to bed, and advised to relinquish control to their physicians. During our study it became evident that some of the men feared that they might be seen as hypochondriacs. For example, one man said that he delayed 6 months for this reason:

*'Oh, well I had some slight irritation [when ejaculating], you know, nothing sort of particular, you know, and I didn't want to be a hypochondriac, and so I delayed going to my GP for a considerable time, maybe for 6 months.'* (T45, aged 55 years, born in former Czechoslovakia, diagnosed 1999.)

Another man, (T41, aged 52 years, diagnosed in 1998), delayed seeking help for 4 months partly because he did not consider the symptoms to be serious, partly because he hated people making a fuss, partly because of embarrassment, partly because he was due to go on holiday, and partly because he did not want to be seen as a hypochondriac. He suggested that help-seeking might affect male image, particularly in the case of younger men. This extract from the interview is quoted at length to show that there may be many reasons for delay and that to understand delay it is important



to understand the patient's past history, as well as the context in which illness occurs:

**T41:** *'I thought it [the problem] would go away. I just thought it was something and nothing ... When I was a child I was always ill, chest infections, asthma, the lot, and my mother always nagged me. And I think it bred in me the fear of mentioning anything, for people fussing around ... I didn't really want to discuss it. I thought it would go away, and that would be it. You know, I wasn't going to be a wimp, you know a hypochondriac ... When I got back off holidays I thought, well I'll make a doctor's appointment. Now I'm still in the mind that it's an embarrassing subject, and when I phoned the doctors they said the male doctor wasn't on, he was on holiday for another 10 days, so I booked an appointment for when he came back ...'*

**I:** *'So the main reason was partly?'*

**T41:** *'Embarrassment.'*

**I:** *'Embarrassment?'*

**T41:** *'Er, not really. I'm not a person that has talked a lot about illness. Er, I don't like people fussing around when I'm ill. If I don't feel well I just go into a corner and that's it ... But I just wanted to go on holiday and not spoil the holiday for anybody and it [the problem] was something I did at work, and it would go away ... And I thought another week [delay] won't make any difference, you know, another week or 10 days or whatever that he [the doctor] was going for his holidays, and I could imagine a young person being really more worried about their image than anything else. You get a lot of bravado about not going to the doctors when you're young and male.'*

**I:** *'Do you?'*

**T41:** *'I think women tend to go to the doctors more, they see more of the doctors. I mean they go to the doctors with pregnancies and things like that. Men don't have things like that, they never go to the doctors. It's not cool to go to the doctors.'*

This man's skilled manual occupation and his age could have some bearing on his attitude to seeking help for his symptoms. Although he remarks that younger men may delay seeking help because of impact on self-image, he has anxieties about being seen as a wimp or a hypochondriac. Bellaby,<sup>32</sup> who studied sickness and absence in a pottery factory in the 1980s, noted that it was unusual for older men to 'give in to sickness' and take time off work. While young, single men might be indulged even if they 'skived off' without being sick, men (and women) with family responsibilities were expected to show stoicism. Bellaby suggests that older manual workers have a particular need to dramatise their 'continuing capacity for manual labour'.

Our findings also suggests that some men delayed partly

because they did not consider it was masculine or 'macho' to seek help. As one man said:

**T39:** *'I suppose because it's the private area ... us men don't like talking about that sort of area or going to the doctor, anything like that. When we have problems we seem to keep it in rather than going to get treatment. But we should really go and get the treatment straight away as soon as you feel anything is wrong.'*

**I:** *'Why do you think men might delay rather than women?'*

**T39:** *'I don't know, it's just the macho part I suppose. I find men don't go to the doctors as much as women do, I find, I personally don't anyway. I've got to be nearly dying before I go to the doctor.'*

**I:** *'And why is that?'*

**T39:** *'I don't know I just, I don't know it's a macho thing I suppose I don't know it's just, I just don't tend to go unless I'm really ill.'*

**Embarrassment.** For many of the men embarrassment contributed to delay in consultation:

*'That was another reason I delayed, the embarrassment of it, which is stupid really, because we are all males, but I suppose it's just one of those male things.'* (T17, aged 54 years, diagnosed 1999.)

In Britain men often use the slang expression 'crown jewels' to describe their genitals, perhaps an indication of the value men give to this part of the body. One man's comments help to explain why men may feel too embarrassed to consult their doctors when they suspect a problem. He is concerned with the size of his penis:

*'I don't really want to go into a doctor's surgery and drop my trousers and get the crown jewels out for him to look at ... I think the main thing [why men delay] is that men are a little bit scared to go [to the doctor] because of dropping their trousers, and being examined by a doctor. And to be honest, those were my concerns at first ... I mean it's a taboo subject with men that, if they're well endowed or they're not well endowed, and perhaps if they're not they might think oh I don't really want the doctor to see it [the penis].'* (T25, aged 28 years, diagnosed 2001.)

Another man delayed seeking help for a few weeks, partly because of embarrassment, and partly because he did not want to admit to himself that he was ill. He suggested that women find it easier than men to consult their doctors about embarrassing issues because women have regular cervical smears and vaginal examinations:

*'I mean it's difficult for men because we don't go to the doctor so often, unlike women, who are forever going to have smears and tests and check-ups. Whereas for men*

*to go and see a doctor is a little embarrassing.*' (T31, aged 40 years, diagnosed 1999.)

**Fear of painful examination.** One man, mentioned above, who delayed seeing his GP for 6 months because he did not want to be seen as a hypochondriac, then delayed going to see a consultant because he found the initial physical examination painful:

**T45:** *'And then when I did go and see this GP, there was a locum, and he gave me an inspection, and I found it quite uncomfortable, the way he went about the inspection. And so I further delayed. You know, he had referred me to somebody else. And I delayed that ...'*

**I:** *'Yes, and when the GP examined you it was, she or he, it hurt a bit, while they examined the testicles?'*

**T45:** *'Yeah, yeah, well you know it's an unglamorous sort of thing to have done and it was excruciatingly painful, you know, I didn't like that, you know, and I don't suppose anyone does like that sort of thing. Anyway, it was my own fault that I delayed the thing.'*

**Fear of the consequences of treatment.** Gascoigne *et al*, reporting the results of their small study, suggest that fear of impotence might be a reason for delay in seeking help.<sup>11</sup> Our study supports this suggestion. One young man delayed seeking help for 6 months because he only had one testicle, and he did not know that testosterone replacement therapy was available. He thought that if he had an orchidectomy his sex life would end:

*'Okay I first discovered I had testicular cancer 18 months ago. One morning while in the bath I realised there was a lump. And I completely ignored it, mainly because I was completely ignorant to what testicular cancer was and I was really afraid of basically losing my sexuality, I was afraid that they would obviously have to cut my testicle off. And it would make more sense if I let you know that I was only born with one testicle, and I think I was so afraid that they would cut my testicle off and I would lose my sexuality that I managed to completely block it out of my mind ... I was almost prepared to put myself in serious danger and let cancer grow inside me rather than let my sexual drive and maybe a bit of my personality [be] taken away from me.'* (T32, aged 26 years, diagnosed 2000.)

**Beliefs about cancer.** Equating the diagnosis of cancer with a death sentence may also lead to delay. One man's mother died of breast cancer 6 weeks before his symptoms developed (T26, aged 39 years, diagnosed 1998). Although he had been told that his mother was cured, she got worse and died. He had lost his faith in doctors' ability to cure cancer and feared he would die if cancer were diagnosed. This led to delay:

**I:** *'So I'm just trying to tease out from you the reason why you delayed going to the GP.'*

**T26:** *'Because I was told that my mum was alright and I thought to myself, well I was told she's alright, now if they tell me I'm alright and then something happens to me, you know I've got a young son as well. And I was thinking you know they told her she was all right for months and she wasn't, she was getting worse and worse day-by-day. And I was frightened that that's going to be me.'*

**I:** *'So it was really fear of going to the doctor?'*

**T26:** *'Yeah, it was fear of actually finding out that you have got it. You know although they say yes it can be cured and all this, it didn't give me much faith because like my mum underwent treatment and operations and radiotherapy and everything else and they said, "Right she's clear." Well if they said to me I was clear and it come back I wouldn't have been a happy bloke.'*

**I:** *'So it was really fear of being told?'*

**T26:** *'It was fear of being told it's spreading. I think that was the thing I was actually scared of the most. But I mean, I'm lucky, because my wife caught it in time.'*

This man finally sought help when his wife saw a programme about testicular cancer on television and 'insisted' he consult his doctor.

**Conflicting responsibilities.** In 1968 Mechanic listed 10 factors known to influence illness behaviour.<sup>13</sup> In that pioneering work he noted that 'needs competing with illness responses' affect response to illness. In our study it was evident that conflicting responsibilities, holidays and busy lifestyles affected how promptly men responded to symptoms. For example, one man noticed that one of his testicles was much firmer than the other one. He delayed seeking advice partly because of embarrassment, but also because of work and family commitments:

*'I then left it, didn't leave it so much, but didn't actually get around to making an appointment; because it's quite awkward with working, you know, a considerable distance from home. And we had a family holiday in August but I had, I did book an appointment for the Monday when we came back, to see the GP.'* (T38, aged 42 years, diagnosed 2001.)

### Misdiagnosis and waiting lists

**Misdiagnosis.** Men reported that after they consulted their GPs, further long delays sometimes occurred because cancerous lumps were confused with cysts, or because their doctors did not recognise some of the less common symptoms of testicular cancer, such as sweating, swollen breasts, sensitive nipples, or backache. One young man discovered a hard lump in one of his testicles but was told not to worry:

*'So I saw the my first GP back in September who told me, "Nothing to worry about, yes there is a lump down there, but nothing to worry about, probably a cyst-type thing." So the lump was still there, and it was getting*

*slightly bigger between September and March of this year and I was getting acute pains as well, sort of doubling up in pain and feeling like a sick pain, made you feel sick. So I saw a second GP in March of this year who said, "I don't think you've got anything to worry about, I think it's a blocked gland but I'll refer you on because you've been twice now and you're obviously concerned about it." So then I did see the specialist about 4 weeks after that, which is probably the end of March, who straightaway examined me and said, "Yeah you've got a tumour in there, that's coming out".'* (T25, aged 28 years, diagnosed in 2001.)

*Delay due to waiting times for consultations or ultrasound investigations.* Further delays may also occur because of waiting times for consultations with hospital specialists or waiting times for ultrasound investigations. For example, in 2001 a man found a lump in his testicle and was too embarrassed to go to his own female doctor. Instead, he went to his local genito-urinary clinic, and the doctor he consulted said that he would arrange an ultrasound, which would take place within 2 weeks. Hearing nothing, he returned to the clinic, and was told that there was a 12-week delay for ultrasound examinations. He then told his mother about the long wait. She had experienced cancer herself and advised him to take some action:

*'She said, "Just keep on at them". So after 10 weeks I rang up again, getting a bit more concerned and agitated about it now, and they said it was going to be about 16 weeks. So I kicked up a bit of a fuss, and I got a date to go into hospital and have the ultrasound test.'* (T20, aged 29 years, diagnosed in 2001.)

## Discussion

### *Summary of main findings and relation to existing literature*

This study builds on previous research, such as the small qualitative study by Gascoigne *et al*,<sup>11</sup> and sheds further light on why some men delay for weeks or even months before seeking help for testicular cancer. Fear of damaging masculine self-image seemed to be an important factor and our study confirmed earlier findings that many men are afraid to admit that they need help.<sup>33</sup> However, it is important to remember that there are many 'masculinities', some hegemonic, some marginalised, and some stigmatised, rather than a single 'masculinity',<sup>34,35</sup> and that male and female 'roles' will vary depending on class, age, and ethnicity.<sup>36</sup> Thus factors such as ethnicity may have an impact on delay. We also found some evidence that a lack of faith in doctors' ability to cure cancer influences delay. Previous experience of cancer within the family, as Gascoigne *et al* suggested,<sup>11</sup> might influence men's willingness to consult, though we also suspect that pessimistic associations with cancer are widespread, irrespective of family history. Thus we have added to understanding about the, sometimes complex, reasons that men report for delay. These relate particularly to masculine self-image. We have also shown that delays occur because of misdiagnosis and waiting

times for ultrasound investigation.

### *Strengths and limitations of the study*

We were able to interview a relatively large number of men in depth about their experiences of testicular cancer, and we have shown that the context in which delays occur, and the patient's previous experience with illness, can affect illness behaviour. We have been shown that reasons for delay may be many and complex. Clearly we were only able to interview survivors, although one of the men who delayed seeking help for 3 months now fears that he only has a few months left to live. The vast majority of men do now survive, but further issues might have been raised had we interviewed more men with terminal illness. Also, other reasons for delay might have emerged had we interviewed more manual workers, and more men from ethnic minority groups. There may be special cultural issues that increase the likelihood of delay but, despite asking GPs and urologists to try to recruit men from these groups, and offering the option of a male interviewer, it was hard to recruit men from minority ethnic groups.

Radley and Billig pointed out that, 'Health beliefs are ideological in that they are sustained within a wider social discourse that shapes not just how individuals think, but how they feel they ought to think.'<sup>37</sup> Given the retrospective nature of this research it is possible that the reasons men gave for delay may have been a rationalisation for past events. The men also reported events that took place weeks, months or even years ago, and they may have forgotten exactly what happened.

### *Implications for clinical practice*

Summerton asserts that 'there is [also] a need for much more clarity about the symptoms and signs of the earlier cancers in the settings when primary care clinicians work and among the patients that they care for'.<sup>38</sup> Our findings show that the diagnosis of testicular cancer can at times be extremely difficult. GPs should maintain a high level of suspicion for men with testicular complaints,<sup>39</sup> and must accept a low threshold for ultrasound investigations of testicular symptoms. A fail-safe agenda should involve patients being told that if they do not hear about an ultrasound scan appointment or outpatient appointment in a certain time, they must make contact so that any administrative errors or delays can be rectified.

To date there is no evidence that routine testicular self-examination is beneficial. It is unlikely that a large, long-term randomized controlled trial of testicular self-examination will ever be carried out, partly because it would be expensive, and partly due to the likelihood of contamination (members of a control group would be liable to drop out of the study, perhaps having read about the importance of self-examination in the media).<sup>40</sup> Some argue that GPs should not spend valuable time teaching men how to examine themselves (except for high-risk groups), and that obsessive self-examination of the testicles may cause undue anxiety and work absenteeism.<sup>40,41</sup> However Vessey,<sup>42</sup> while not supporting 'ritualistic' self-examination, suggests that men should at least be aware of the normal shape and feel of their testicles, rather like the breast awareness campaign for women. If men are aware of what is nor-



mal for them they are more likely to consult when appropriate rather than gaining false reassurance from the absence of a lump. Efforts should be made to make men aware that serious disease may be present even in the absence of pain. It is also important that men know that the treatment for testicular cancer does not usually lead to long-term sexual problems, and that unless both testicles are involved, fertility is not affected and men's sense of masculinity is usually maintained.<sup>43,44</sup> This information might encourage men to seek help.

Several men said that they decided to seek help after they had read about testicular cancer in magazines, newspapers or practice leaflets, or after they or their wives had seen television programmes about testicular cancer. Recently, Cancer Research UK has run a campaign called 'Dads and Lads — Are you on the ball?', and England Football Team manager Sven-Goran Eriksson and Gordon Taylor, the chief executive of the Professional Footballers Association, have helped to raise awareness of testicular cancer. Other high profile sportsmen, such as Tour de France winner Lance Armstrong, and rugby player Chris Horsman, have written about their experiences of testicular cancer.<sup>45,46</sup> Perhaps more such accounts will encourage men to seek advice promptly. It is important that men know the signs and symptoms of testicular cancer, but equally important that they understand that a diagnosis of testicular cancer is not a death sentence and that the cure rate is excellent. Men also need easy access to doctors, at surgeries where they feel welcome, and to clinics where they can seek advice without embarrassment.<sup>47</sup> However, even in these circumstances well informed men may still delay. As our study and other studies have shown, many complex factors influence illness behaviour for men with testicular cancer.

## References

- Power D, Brown R, Brock C, *et al.* Trends in testicular carcinoma in England and Wales, 1971-1999. *BJU Int* 2001; **87**: 361-365.
- Dearnaley D, Huddart R, Horwich A. Managing testicular cancer. *BMJ* 2001; **322**: 1583-1588.
- Wishnow K, Johnson D, Preston W, *et al.* Prompt orchiectomy reduces morbidity and mortality from testicular carcinoma. *Br J Urol* 1990; **65**: 629-633.
- Moul J, Paulson D, Dodge R, Walther P. Delay in diagnosis and survival in testicular cancer: impact of effective therapy and changes during 18 years. *J Urology* 1990; **143**: 520-523.
- Hernes E, Harstad K, Fossa S. Changing incidence and delay of testicular cancer in southern Norway (1981-1992). *Eur Urol* 1996; **30**: 349-357.
- Toklu C, Ozen H, Sahin A, *et al.* Factors involved in diagnostic delay of testicular cancer. *Int Urol Nephrol* 1990; **31**: 383-388.
- Chilvers C, Saunders M, Bliss J, *et al.* Influence of delay in diagnosis on prognosis in testicular teratoma. *Br J Cancer* 1989; **59**: 126-128.
- Bosl G, Goldman A, Lange P, *et al.* Impact of delay in diagnosis on clinical stage of testicular cancer. *Lancet* 1981; **2**: 970-973.
- Pill R. Issues in lifestyles and health: lay meanings of health and health behaviour. In: Badura B, Kickbusch I (eds). *Health promotion research*. Copenhagen: World Health Regional Office for Europe, 1991: 187-211.
- Steele J, Oliver R T. Testicular cancer: perils of very late presentation. *Lancet* 2002; **359**: 1632-1633.
- Gascoigne P, Mason M, Roberts E. Factors affecting presentation and delay in patients with testicular cancer: results of a qualitative study. *Psychooncology* 1999; **8**: 144-154.
- Koos E. *The health of Regionville: what the people thought and did about it*. New York: Columbia University Press, 1954.
- Mechanic D. *Medical sociology*. New York: The Free Press, 1968.
- Zola I. Pathways to the doctor: from person to patient. *Soc Sci Med* 1973; **7**: 677-689.
- Blaxter M. The causes of disease. Women talking. *Soc Sci Med* 1983; **17**: 59-69.
- De Nooijer J, Lechner L, de Vries H. Help-seeking behaviour for cancer symptoms: perceptions of patients and general practitioners. *Psychooncology* 2001; **10**: 469-478.
- Mor V, Masterson-Allen S, Goldburg R, *et al.* Pre-diagnostic symptom recognition and help-seeking among cancer patients. *J Community Health* 1990; **15**: 253-266.
- Smith E, Anderson B. The effects of symptoms and delay in seeking diagnosis on stage of disease at diagnosis among women with cancers of the ovary. *Cancer* 1985; **56**: 2727-2732.
- Burgess C, Hunter M, Ramirez A. A qualitative study of delay among women reporting symptoms of breast cancer. *Br J Gen Pract* 2001; **51**: 967-971.
- Oliveria S, Christos P, Halpern A, *et al.* Patient knowledge, awareness, and delay in seeking medical attention for malignant melanoma. *J Clin Epidemiol* 1999; **52**: 1111-1116.
- Department of Health. *Referral guidelines for suspected cancer*. London: HMSO, 2000.
- Dyer O. London hospital slated for 'chaotic' ultrasound service. *BMJ* 2002; **325**: 1193.
- Coyne I. Sampling in qualitative research. Purposeful and theoretical sampling: merging or clear boundaries? *J Adv Nurs* 1997; **26**: 623-630.
- Pope C, Ziebland S, Mays N. Analysing qualitative data. *BMJ* 2000; **320**: 114-116.
- Richards L, Richards T. The transformation of qualitative method: Computational paradigms and research processes. In: Fielding N, Lee R (eds). *Using computers in qualitative research*. London: Sage, 1993: 38-53.
- Tesch R. *Qualitative research: analysis types and software tools*. New York: Falmer Press, 1991.
- Malterud K. Qualitative research: standards, challenges, and guidelines. *Lancet* 2001; **358**: 483-488.
- Morse JM. 'Perfectly healthy but dead': the myth of inter-rater reliability. *Qual Health Res* 1997; **7**: 445-457.
- Gwyn R. *Communicating health and illness*. London: Sage, 2002.
- Chapple A, Ziebland S. Prostate cancer: embodied experience and perceptions of masculinity. *Soc Health Illness* 2002; **24**: 820-841.
- Lupton D. *Medicine as culture*. London: Sage, 1994.
- Bellaby P. What is genuine sickness? The relation between work-discipline and the sick role in a pottery factory. *Soc Health Illness* 1990; **12**: 47-68.
- Seidler V. *Man enough: embodying masculinities*. London: Sage, 1997.
- Morgan D. 'You too can have a body like mine': reflections on the male body and masculinities. In: Scott S, Morgan D (eds). *Body matters: essays on the sociology of the body*. London: The Falmer Press, 1993.
- Connell, R. *Masculinities*. Cambridge: Polity Press, 1995.
- Moynihan C. Men, women, gender and cancer. *Eur J Cancer Care* 2002; **11**: 166-172.
- Radley A, Billig M. Accounts of health and illness. *Soc Health Illness* 1987; **9**: 220-240.
- Summerton N. Cancer recognition and primary care. *Br J Gen Pract* 2002; **52**: 5-6.
- Austoker J. *Cancer prevention in primary care*. London: BMJ Publishing Group, 1995.
- Westlake SJ, Frank JW. Testicular self-examination: An argument against routine teaching. *Fam Pract* 1987; **4**: 143-148.
- Hopcroft K. Routine testicular self examination — a load of balls (letter). <http://www.bmj.com/cgi/eletters/323/7320/1058> (accessed 26 Nov 2003).
- Vessey M. Men and the NHS (letter). <http://www.bmj.com/cgi/eletters/323/7320/1058> (accessed 26 Nov 2003).
- Gordon D. Testicular cancer and masculinity. In: Sabo D, Gordon D, (eds). *Men's health and illness: gender, power and the body*. London: Sage, 1995: 246-265.
- Moynihan C. Testicular cancer: the psychosocial problems of patients and their relatives. *Cancer Surv* 1987; **6**: 477-509.
- Armstrong L. *It's not about the bike: my journey back to life*. London: Yellow Jersey Press, 2001.
- Halle M. It's still such a taboo condition, but I'm not shy any more — losing one of my testicles to cancer should be a warning to all men. *Daily Mail* 1999; **13 July**: 45.
- Banks I. No man's land: men, illness and the NHS. *BMJ* 2001; **323**: 1058-1060.

## Acknowledgements

We thank the men who gave us the interviews, and those who helped to recruit volunteers. We should also like to thank Andrew Herxheimer, Sasha Shepperd, Rachel Miller, Aidan McFarlane, Joan Austoker, David Mant, and two anonymous referees for their useful comments on an earlier draft of this paper. The study was funded by The Department of Health and Macmillan Cancer Relief.