

**ORIGINAL RESEARCH**

# Barriers to diagnosis and accessing effective treatment and support for testosterone deficiency

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(Janine David)**Abstract**

Testosterone deficiency is common but often undiagnosed and untreated with many men struggling with symptoms for years before reaching out for healthcare professional advice. In order to gain an holistic view of the barriers to men accessing effective treatment, this qualitative study captures the behaviours, beliefs and experiences of all key stakeholders: men with testosterone deficiency, general practitioners (GPs) and endocrinologists. The main findings include a lack of awareness and knowledge of the range of symptoms of testosterone deficiency amongst men and GPs, and stigma and embarrassment inhibiting open, proactive discussions between men and GPs and limiting diagnosis. Endocrinologists believe many men referred to them could be appropriately managed by GPs. Endocrinologists' responsibility is to assess and provide appropriate treatment for more complicated cases, which often involves additional investigations that men are not expecting and might not result in treatment with testosterone therapy.

**Keywords**

Testosterone deficiency; Testosterone therapy; Patient research

## 1. Introduction

Testosterone deficiency (TD) is common in men aged over 40 and has a considerable impact on quality of life, well-being and long-term health outcomes [1]. Sexual symptoms include loss of early morning erection (EME), erectile dysfunction (ED) and loss of libido, while other non-specific symptoms include decreased muscle mass and strength, fatigue, sleep disturbances, changes in mood and decreased cognitive function [1]. The estimated incidence of symptomatic TD in men aged 40–70 years varies between 2.1 and 5.7% [2] with an estimated prevalence of as much as 38.7% [3] depending on the criteria used to diagnose TD. The British Society for Sexual Medicine (BSSM) recommends that treatment with testosterone therapy should be initiated in symptomatic men with a total testosterone level <12 nmol/L or free testosterone <225 pmol/L (<0.225 nmol/L) from two separate morning samples between 8 AM and 11 AM [1].

Despite evidence-based guidelines recommending investigation of testosterone levels in symptomatic men and those considered at risk of TD including men with diabetes, osteoporosis, cardiovascular disease, obesity, anaemia, men taking long-term opiate therapy [1, 2], and men who have undergone orchidectomy [4], many men with TD are still undiagnosed and untreated [1, 5, 6].

In order to understand the complete, holistic picture of the barriers preventing men with symptoms of TD from being diagnosed and accessing support and appropriate treatment, we conducted in-depth qualitative research with men, GPs

and endocrinologists. We used a qualitative methodology to enable us to cross-refer and explore issues raised by different stakeholders with each other in order to fit the different pieces together to identify the issues and how they might be addressed.

## 2. Materials and methods

The study used a qualitative methodology with in-depth 60-minute interviews to explore and understand the perspectives of men with TD, GPs and endocrinologists with respect to the detection and management of TD.

Men reporting symptoms of testosterone deficiency were recruited from a large opt-in consumer panel. Social media was also used in order to reach a fully representative sample of men, including from specific ethnic groups. Endocrinologists and GPs were recruited from opt-in panels of healthcare professionals (HCP) who had consented to be contacted to participate in research. Both the consumer and HCP panels are regularly maintained with demographic characteristics updated to ensure appropriate sample selection. All participants received payment for their participation in line with regulatory guidelines and fair market value rates. Men with TD, GPs and endocrinologists were recruited from different geographical regions of England (London, South East, South West, East and West Midlands and the North), Scotland, Wales and Northern Ireland. Three groups of men were recruited: those who were diagnosed and treated with testosterone therapy; men diagnosed but not on testosterone therapy either because they had

not been offered it or they had refused, and men with symptoms indicative of TD as defined by the Androgen Deficiency in Aging Males (ADAM) questionnaire. These men had not been assessed by a doctor in relation to their symptoms and had not had their testosterone levels measured so may have had an alternative explanation for their symptoms. They were not on testosterone therapy.

Two semi-structured interview schedules were designed to ensure that critical topics were covered in both the men and HCP interviews. Topics covered in the interviews with men included: symptoms of TD, attitudes to seeking healthcare advice and knowledge and beliefs about testosterone therapy. In addition to these topics, HCPs were also asked about diagnosis, investigations, referral procedures and preferred management. Interviews were conducted face-to-face and remotely *via* video call. The interviews were recorded and subsequently transcribed for analysis.

A grounded theory influenced approach was used to ensure a systematic process was followed in developing knowledge and theory [7]. Analysis started in parallel with data collection. Two trained researchers worked independently to identify and code statements of interest and draw out recurring themes. Both researchers had received training in qualitative methodology as part of their post-graduate degrees (MSc in Health Psychology, PhD in medicine (patient outcomes)) and many years of experience as qualitative researchers in healthcare. Memos were written about emerging categories, to summarise a point, to critique information and to relate emergent theories to existing literature. In accordance with the grounded theory approach, data were constantly compared until “theoretical saturation” was reached and no new categories or themes emerged. Researchers compared and discussed their findings to ensure reliability and reduce bias.

## 3. Results

### 3.1 Sample

Twenty interviews were conducted with the three groups of men aged 45 to 62 years. The men represented diverse ethnic groups, a range of educational levels from finishing full-time education aged 16 years to completing post-graduate education and were recruited from different geographic locations. Six had been diagnosed with TD and were taking testosterone therapy, six had been diagnosed with TD but were not taking testosterone therapy and eight men were undiagnosed but experiencing symptoms and were not on testosterone therapy. Interviews were also undertaken with 30 GPs and 10 endocrinologists from different geographic locations around the UK.

### 3.2 Living with TD

Men in all three groups initially experienced loss of energy and increased fatigue but the key symptoms which caused most concern and had the greatest impact on their well-being, self-esteem, self-confidence and relationships were loss of libido and erectile dysfunction. They also described decreased enjoyment of life, feeling sad and grumpy, falling asleep after dinner and falling asleep in general.

*“The whole thing started some years ago, I can’t remember*

*how long, but some years ago I had problems with my sex life. At that time, I was with my wife and it was causing problems because although we were becoming middle-aged or late middle-aged she was still sexually active and my ability was rapidly disappearing. And so I tried to find a solution to this, which was mainly erection problems and it turned out that I had very low testosterone.”* (Man diagnosed with TD and receiving treatment with testosterone therapy)

*“Well, I mean, definitely (most worried about) the decrease in libido..... As a gay man, I’ve got the apps on my phone and I was literally thinking, “You know what, I could delete those. I’m not meeting anybody. It’s not like as if I’ve got any interest.” Yeah, that was quite telling for me to be thinking, oh, I might as well just delete all those.”* (Man diagnosed with TD, not receiving treatment with testosterone therapy)

*“I think the highest priorities would be the decrease in libido, decrease in strength and endurance, decreased enjoyment of life.”* (Man with symptoms but not diagnosed with TD)

### 3.3 Barriers to accessing treatment: men

Themes that emerged as barriers to seeking help, accessing and accepting treatment and support are listed in Table 1.

#### 3.3.1 Barriers to seeking help: men

##### 3.3.1.1 Slow, gradual onset of non-specific symptoms like fatigue, loss of energy and loss of muscle strength mean that these are often normalised or misattributed

Men in all groups report the onset of non-specific symptoms such as fatigue was usually gradual, often over a 5–10-year period and as a result, men in all groups did not recognise it as a symptom of an underlying condition, but rationalised it as:

- Slowing down with age
- Resulting from prolonged stress or pressure at work
- Due to hard work/exercise
- The aftermath of minor illness—similar to long COVID

Loss of energy was rarely a reason for them to seek help from their GP. Reduced energy and increased fatigue themselves only triggered men to seek medical help when these symptoms prevented them from performing their normal activities (*e.g.*, usual level of exercise), threatened their job, or when they wanted to exclude serious causes such as cancer.

##### 3.3.1.2 Lack of awareness and knowledge of TD or the associated symptoms including loss of libido and erectile dysfunction

Men do not necessarily equate loss of libido or erectile dysfunction to low testosterone. Only those very few men who knew someone with TD and who had spoken with them about it were aware of the link between these sexual symptoms and other symptoms, such as loss of energy, fatigue, decreased muscle mass, and that this combination of symptoms might signify TD. Even those men who had Google searched for these individual symptoms were not aware of the link between them. Each symptom was considered and addressed separately.

**TABLE 1. Barriers to men seeking help and accessing support.**

Barriers to seeking help	Barriers to accessing/accepting treatment and support
Slow, gradual onset of non-specific symptoms like fatigue, loss of energy and loss of muscle strength mean that these are often normalised or misattributed (deliberately as rationalisation or because of lack of knowledge)	Limited information exchange with the GP made TD more difficult to diagnose
Lack of awareness and knowledge of TD or the associated symptoms including loss of libido and erectile dysfunction	Beliefs and perceptions of testosterone therapy based on use as a body building supplement and concerns about side effects
Stigma, embarrassment, identity, “machismo”, not wanting to associate with everything testosterone represents to them or from a societal view, meaning symptoms are not discussed or admitted to	Limited or no information supporting the decision to use testosterone therapy: how to take it, how long for, long-term safety, long-term benefits and concerns not addressed
Belief that the doctor will not be interested in their symptoms—that they are not due to a medical condition but related to ageing	Variable experiences of endocrinology appointments
Self-treatment with relaxation, supplements, tonics and pharmacy treatments, e.g., Viagra Connect	

TD: Testosterone deficiency; GP: General Practitioner.

### 3.3.1.3 Stigma, embarrassment, identity, "machismo", not wanting to associate with everything testosterone represents to them or from a societal view, meaning symptoms are not discussed or admitted to

All men were uncomfortable discussing sexual symptoms with their doctor. They described a significant stigma attached to erection problems that prevented them from discussing their symptoms with friends and an embarrassment in discussing them with their doctor, especially if the doctor was female. They felt less manly, inadequate, depressed and that they were failing their partners. As with loss of energy, they rationalised their sexual issue as the result of stress, fatigue, anxiety and age.

*“It’s kind of like...I bet you (doctor) don’t suffer with this and therefore you’re, kind of, sniggering at me under your breath.”* (Diagnosed with TD)

For almost all men who had sought medical help for their TD, loss of libido or erectile dysfunction were the key symptoms triggering help-seeking. These men had overcome the embarrassment and stigma to ask for help even though many were still unable to discuss their symptoms with anyone else, including their partner. For some men, there was a concern that the underlying cause for their sexual problems might be something serious, like cancer, but the necessity to get help/treatment was usually driven by a need to “fix” this issue for the sake of their relationship.

*“I went to a GP and said that I was having marital problems because my sexual ability was disappearing.”* (Diagnosed with TD and receiving treatment)

*“Are these an indication of something more sinister, more serious? That’s something I would want to know. Is it normal for a bloke of my age? Could it be an indicator of something bad starting or that I have something bad? Those are the questions I’d want to know. And also, can it be fixed? Is there something that I could be doing to fix it?”* (Undiagnosed)

*“But then you do start to think that perhaps there are other things and you start to think, well, decreasing strength and*

*endurance and lack of energy, is it something else? ‘Cause lack of energy is often; I’ve had a couple of mates that have unfortunately been diagnosed with cancer. They’re okay now but one of the key indicators was lack of energy. So, you do start to look online but that’s one of the most dangerous things you can do, isn’t it? Yeah, Dr. Google tells you you’re dying of everything.”* (Diagnosed)

### 3.3.1.4 Belief that the doctor will not be interested in their symptoms—that they are not due to a medical condition but related to ageing or self-treatment with relaxation, supplements, tonics and pharmacy treatments for erectile dysfunction

Undiagnosed men who had not sought help believed that the GP would not be interested as it is “not a real medical condition”. They accommodate and manage the individual symptoms themselves such as through exercise, relaxation, tonics, energising supplements, vitamin supplements and purchasing Viagra Connect from a pharmacy, usually an online pharmacy to avoid embarrassment.

*“I’ve sort of self-diagnosed a little bit. You think lack of energy, maybe I need to eat more fruits. The lack of energy has got better this last month because I’ve started to go to the gym regularly and just do cardio. I’m running a lot. I’m cycling a lot.”* (Undiagnosed)

*“It’s probably a pride thing, the male pride. Just needing any kind of intervention, of course, I’m the chap who wouldn’t need that kind of thing. And it’s probably sort of embedded deep in my psyche that you don’t get medical intervention, or you fix your own problems.”* (Undiagnosed)

## 3.3.2 Barriers to accessing/accepting treatment and support: men

### 3.3.2.1 Limited information exchange with the GP made TD more difficult to diagnose

Men report that getting a diagnosis of TD could take several months or years depending on the presenting symptoms. Limited consultation time makes it difficult to have a meaningful

conversation, especially when men need to overcome embarrassment, and feeling rushed means they may not report all of their symptoms.

*“I was back and forwards to the doctor. They did blood tests and initially, they tried to put it down to high blood pressure. It was brought under control, I still had the ongoing issues and I kept pushing it, and I did a lot of research myself then. My testosterone levels... they always said were okay... But when I did the research, I basically found out the fact that they believe if your testosterone level is always at the low end of the spectrum, over a period of time, it will create problems... So, with that information... they organised for me to see the endocrinologist... and... she felt that I should have been there years before.”* (Diagnosed, treated with testosterone therapy)

When men were diagnosed with TD they often had conflicting emotions. There was the relief of getting an explanation for their symptoms and the hope and expectation of treatment, but the emotional response to being told they had low testosterone was often negative. Some described feeling left a little in limbo, not sure what it meant or what the next steps should be.

*“(I felt) annoyed, angry, hurt, and probably, I wouldn’t say depressed, but disbelieving. It sort of was like, oh, it can’t be, hopefully it’s not me, I hope it will go away. Inside, I didn’t want to address it, and because it’s so emotional, it’s really overwhelming. I did not want to address it. Because you’re only in the doctor’s surgery for so long, you just don’t want to address it sometimes. It’s like you’re told something and then you don’t want to believe it. It took a long time for me to believe this, by the way.”* (Diagnosed, treated)

*“I was annoyed that it had taken so long to get to this point. Felt.... happy that there was now an answer to it that I could put a name to something. I suppose I was hopeful for the future and that this (treatment) would improve me and my life.”* (Diagnosed, treated)

*“He looked at the screen, he said, “Yes, you’re right, you’ve got low testosterone, levels of whatever he said”, and he put it down to age and he just dismissed it, and the more I asked him about it, “Is there treatment?” he sort of swept over it. In other words, he wasn’t interested, it was like a nuisance.”* (Diagnosed, untreated)

### 3.3.2.2 Beliefs and perceptions of testosterone therapy based on use as a body building supplement and concerns about side effects

Amongst the men who were diagnosed but untreated, some had refused to take testosterone therapy because of the association of testosterone with body building supplements, and consequent concerns about its safety and appropriateness as a treatment. They also believed that testosterone can cause aggression and other side effects.

*“The only (times I’d heard of people) injecting testosterone were gym users and (in) road rage (situations).”* (Diagnosed, not treated)

*“I’m perfectly alright with taking medicines, taking hormones, as long as they don’t have negative effects. I know everything has some side effects, but it seems around testosterone there’s too many side effects that I’m not willing to accept yet, and I think maybe in a few years I will be willing to accept*

*them, but not at the moment.”* (Diagnosed, not treated)

### 3.3.2.3 Limited or no information supporting the decision to use testosterone therapy: how to take it, how long for, long-term safety, long-term benefits and concerns not addressed

Following diagnosis or initiation of treatment, men report being given limited or no information about taking testosterone therapy. They either accept what information they have been given or do background research of their own or search online. They tend to access only what they consider to be verified websites, e.g., NHS, [patient.co.uk](http://patient.co.uk) and Mayo Health Clinic, or search for forums and other sites including Google where they might find additional information or read about the experiences of someone like themselves. With the exception of the forums, men report that there is very little information available and what is available is so generic that they do not find it helpful as they cannot recognise themselves or their situation in the information.

*“Well, I think they could have explained a bit more about why it was happening and how it happens and things. You know, I really don’t even know to this day why you get low in it (testosterone). In my own (case), I just presume it’s as you get older it sort of disappears a bit. But I don’t really know why.”* (Diagnosed, treated)

### 3.3.2.4 Variable experiences of endocrinology appointments

Whilst men are relieved that they have been referred to an endocrinologist, the consultations themselves were variable in quality from very informative and supportive, helping men to understand TD and what the next steps were, to awkward and/or disappointing because men did not get the information they wanted. Men are frustrated that they did not necessarily start treatment immediately after they were referred. Where the endocrinologist did not think testosterone therapy was the right treatment, men feel that they were given very negative information designed to put them off taking it, for example, that it would make them more aggressive.

*“I was not so much bothered about the diagnosis. I wanted some medication, either Viagra or testosterone, which would reverse it.”* (Diagnosed, untreated)

*“Excellent consultation with the endocrinologist who explained everything and used the analogy of the menopause. This made sense.”* (Diagnosed, treated)

## 3.4 Barriers to providing treatment for TD: GPs

### 3.4.1 GP attitudes and beliefs

The interviews revealed marked variation in care, with three clear groups of GPs who have different approaches to diagnosis and management of TD:

1. A small number of specialist GPs who believe TD is clinically or psychologically important and understand the benefits of treatment outweigh any concerns or risks. These GPs generally diagnose and treat TD themselves without referral to endocrinologists unless there are complex comorbidities.
2. The majority of GPs who are less knowledgeable but believe TD should be treated. They are concerned about the

potential risks and always refer their patients to endocrinologists for confirmation of diagnosis and treatment initiation, then take responsibility for ongoing care.

3. A small number of GPs who do not consider TD to be clinically important, are not convinced about the necessity for treatment and have concerns about efficacy and side effects. They are more likely to offer lifestyle advice and rarely refer to an endocrinologist. Some of these GPs question whether TD is a medical condition or just a normal process.

Themes that emerged as barriers to GPs diagnosing TD and offering testosterone therapy are listed in Table 2.

### 3.4.2 Barriers to diagnosis: GPs

Low libido or erectile dysfunction are the main triggers for GPs in all three groups to consider TD and to check testosterone levels. Despite the fact that loss of energy is an almost universally experienced symptom it rarely raises suspicion of TD in any but the small group of “specialist” GPs. As it is so nonspecific, men would be investigated for other conditions first and only have their testosterone levels checked incidentally or once all other diagnostic options had been excluded.

This lack of knowledge of the multiple symptoms of TD means that misattribution of symptoms is common, particularly low mood which is often treated as depression by all groups of GPs, without consideration of the possibility of TD, and can subsequently lead to delays in diagnosing TD. GPs in all three groups feel comfortable explaining low testosterone in relation to ageing in older men. With the exception of the more specialist GPs, the other groups are more challenged when providing explanations for complicated scenarios including: younger men, younger men with fertility issues and men with diabetes or other comorbidities.

Proactive conversations initiated by GPs about TD occur rarely. Sexual dysfunction is still a taboo subject so some GPs do not like to start a conversation about it, and lack of knowledge of some of the other symptoms of TD also limits these conversations. In addition to a lack of knowledge about the multiple symptoms of TD, there was a lack of awareness of the potential long-term consequences of untreated TD, for example osteoporosis, and the possibility of an increased risk of cardiovascular events, coronary heart disease, and cerebrovascular disease [8]. This contributed to the perception held by some GPs that TD is not clinically important but represents a natural ageing process and therefore is not a clinical priority or important to investigate and treat.

### 3.4.3 Barriers to offering testosterone therapy: GPs

Whilst specialist GPs are very knowledgeable and happy to prescribe testosterone therapy with or without discussion with an endocrinologist, the majority of GPs lack knowledge about testosterone therapy and refer men to an endocrinologist to make decisions on treatment. They then take over prescribing and monitoring in a shared care model.

The minority of GPs who do not consider TD to be clinically important often have concerns about side effects of testosterone therapy and whether there is a long-term increased risk of prostate cancer. GPs in this group are more likely to empower men to improve unhealthy lifestyles such as ad-

dressing obesity and excess alcohol use rather than refer them to an endocrinologist. Concerns about abuse such as using testosterone for bodybuilding were also expressed.

*“I think if someone has got a lifestyle that’s reasonable, I think that’s okay. I suppose I’ve got a little bit of a concern about this. We’re giving testosterone and I know that people—well as men get older, we’ve got more exposure to testosterone we’re getting more prostate cancer. So, my concern is what is the long-term data? Are we increasing this gentleman’s chance of getting a prostate cancer? It doesn’t matter, I suppose, if they just get diagnosed, but is that prostate cancer going to shorten his life? When I heard a consultant speak about it, they didn’t seem too concerned but yet they didn’t fully reassure me that that was okay.”*

GPs voiced a lack of experience in managing men on testosterone therapy. They worry that gels could be misused or sold on, but that injectables are long-acting and so any side effects are harder to immediately address. There is a lack of general knowledge about how often testosterone levels should be checked.

*“So, I don’t know enough about the fluctuations in testosterone levels myself to understand how often these men should (have these levels repeated). Because we’re not (doing it). Maybe in a couple of years’ time if they’ve had low levels. So yes, I think it’s quite a lack of, in my mind, understanding of how testosterone behaves over the years really.”*

Only the small group of specialist GPs have good awareness of the long-term benefits of testosterone therapy and the belief that these benefits outweigh any concerns or risks.

*“Yes, it is a necessary treatment in the group of patients that we have found to have low testosterone. We know it’s an evidence-based treatment and men do benefit from it, otherwise (why) would they want to go on having treatment for it? When we are talking about concerns, there is always a concern about anything that I am putting into any patient’s body, but if I have made sure that I have assessed the patient appropriately and looked for anything which might make them more at risk of the side effects of testosterone, (then I am confident to initiate treatment).”*

## 3.5 Barriers to providing treatment for TD: endocrinologists

Endocrinologists are generally positive about testosterone therapy, recognise TD as a clinically important condition requiring treatment because of the long-term health consequences and believe that treatment should be initiated as soon as possible. However, referral to an endocrinologist and confirmation of TD does not necessarily mean that men will receive treatment with testosterone therapy. There are a number of challenges and alternative treatment options or approaches. Themes identified are listed in Table 3.

### 3.5.1 Challenges in confirming a diagnosis of TD: endocrinologists

Endocrinologists describe their role and responsibility as undertaking whatever investigations are necessary to confirm a diagnosis of TD, or to make an alternative diagnosis, and to then initiate the appropriate treatment. In some more complex

**TABLE 2. Barriers to GPs diagnosing TD and offering treatment.**

Barriers to diagnosis	Barriers to offering testosterone therapy
Lack of knowledge or recognition of symptoms other than loss of libido and erectile dysfunction	Lack of knowledge about testosterone therapy and other treatment options
Lack of knowledge about TD, the distinction between primary and secondary TD and age-related considerations, and the link between TD and many common conditions	Lack of confidence in using testosterone therapy resulting in reluctance to take responsibility and either not offering treatment or referring to specialist (endocrinologist) with consequent delays in treatment
Misattribution of symptoms to another cause or condition, e.g., depression, therefore causing delays in diagnosis of TD	Belief that TD can be managed through lifestyle modification
Avoiding embarrassing or difficult conversations so men are not proactively asked about TD symptoms	Lack of experience in managing men on testosterone therapy
Beliefs and perceptions of testosterone deficiency as a natural process and not an illness	Lack of awareness of the clinical importance of TD and long-term health outcomes and the benefits of testosterone therapy

*TD: Testosterone deficiency.*

**TABLE 3. Barriers to endocrinologists diagnosing TD and offering treatment.**

Challenges in confirming diagnosis	Barriers to offering testosterone therapy
Complex cases requiring further investigations	Some straightforward cases can be managed in primary care, others require specialist or shared care models
Need for treatment to stabilise underlying health conditions before TD diagnosis	Concerns about side effects
No standardisation of testosterone levels and what is considered “low”	Perceptions of efficacy in relation to sexual dysfunction
	Lack of consensus about use of testosterone therapy in men with previous prostate cancer

*TD: Testosterone deficiency.*

cases, they will retain responsibility for monitoring patients. Endocrinologists need to identify whether the low testosterone identified by the GP, through diabetes screening, or by their secondary care colleagues is the result of primarily gonadal or primarily pituitary problems, or due to some other cause such as obesity, diabetes and some medications.

Men with conditions that can cause low testosterone will be treated first for their underlying conditions and this might return testosterone levels to normal, meaning that TD is not the diagnosis.

The need for further investigations to confirm the diagnosis of TD, and the treatment of underlying conditions to potentially return testosterone levels to normal do not fit men’s expectations of the referral, in that they thought they had been referred to be prescribed testosterone therapy. This can be frustrating for endocrinologists who have to manage these disappointed expectations.

*“Generally speaking, if a male individual has low libido, testosterone seems to be one of the things they always think about. In a lot of patients, you do the testosterone level and it’s normal, and then I tend to reassure them this is not a testosterone problem, and I think that’s the slight difficulty with some of these symptoms I’ve mentioned, because they could overlap with other medical conditions. I mean, patients may just simply be low in mood, depression, which can cause low*

*libido, not as a direct consequence of testosterone deficiency. Or if someone is very obese, that naturally lowers the measured testosterone level and treating obesity can boost up the total testosterone, (without) giving them testosterone replacement.”*

Amongst endocrinologists, there is variation in what level of testosterone is considered to be low and when treatment should be initiated. Some endocrinologists will initiate treatment if total testosterone levels are below 8 nmol/L (consistent with the BSSM definition of TD [1]), whilst others use a lower 5.6 nmol/L cut-off. Several endocrinologists initiate treatment for a three month “trial” in symptomatic men with borderline testosterone levels of between 8 nmol/L and 12 nmol/L as recommended by the BSSM, whilst others do not. One of the challenges discussed by endocrinologists is that the assay and guidelines do not take account of age in determining “normal” testosterone levels and there is currently no consensus within the speciality as to how to address this.

*“So what I do is, if the level is less than 7, I just say this is low. If the level is more than 14, I just say that is normal, I’m not going to investigate any further, right. So I’m usually between that 8 to 12 and 13 range, and when the patients are in that range, if they have symptoms, I calculate their free testosterone. And if the free testosterone then looks like it’s on the lower side and the patient has symptoms, then I would treat the patient.”*

*“I think the first thing to say is it’s a bit of a controversial area because there’s no real consensus within the specialty as to what actually constitutes hypogonadism in older men. One of the problems is that we use a one-size-fits-all approach for the assay for testosterone. The assay range that we use is the same for an 18-year-old man as it is for an 80-year-old man. Unfortunately, it’s not age specific. I think it certainly should be, but it’s not. As everyone knows testosterone tends to drop in men as they get older. So the question is, what is just the physiological drop in testosterone and what is actually hypogonadism and as I said, there’s no real consensus on that.”*

### **3.5.2 Barriers to offering testosterone therapy in secondary care: endocrinologists**

Endocrinologists express some frustration in the type of cases referred to them, believing that the majority of straightforward cases should be managed in primary care, with advice if required. They feel that their service should be restricted to more complex cases which they would manage themselves or through a shared care model with the GP.

*“The thing is TRT (testosterone replacement therapy) is seen to be quite a specialist area, although probably most GPs could manage it okay, it is seen to be quite a specialist area.”*

Sexual dysfunction is usually the main concern of men, but endocrinologists feel that in most instances testosterone therapy does not effectively resolve this symptom. The addition of a phosphodiesterase type 5 (PDE5) inhibitor is felt to be useful.

*“You have to give them a realistic expectation that testosterone treatment (won’t) just suddenly lead to a massive boost in libido because a lot of other factors do play a role, be it libido or erectile difficulties.”*

When considering the pros and cons of prescribing testosterone therapy, endocrinologists look at the relevant potential side effects for each individual in the context of their age, fertility needs and comorbidities. There are differing opinions on whether testosterone therapy increases the risk of prostate cancer; some endocrinologists believe there is no link whilst others feel that the “jury is still out”. Consequently, there is a lack of consensus about use of testosterone therapy in men with previous prostate cancer and some endocrinologists would seek advice from a urologist prior to prescribing testosterone therapy.

*“(There are) always concerns that there are contraindications, the more prominent in relation to prostate cancer. There are a lot of misconceptions about that. There was this misconception that TRT causes prostate cancer which is actually not true. If there’s no underlying prostate problem then it is fine to use testosterone. It’s only an issue if there’s underlying prostate cancer or abnormal prostate cells or whatever, then obviously in those situations TRT can actually make the problem worse.”*

### **3.6 Fitting the picture together: demonstrating how the different barriers for men, GPs and endocrinologists interact to deny men access to diagnosis and effective treatment**

Lack of awareness and knowledge of the multiple symptoms of TD by men and by GPs is a major barrier to men receiving a diagnosis and accessing appropriate treatment, often leading to misattribution of symptoms and delayed diagnosis of TD. Embarrassment and stigma inhibit men and GPs from discussing sexual dysfunction in consultations about other non-specific symptoms, which can make TD more difficult to diagnose.

When testosterone levels are checked and found to be low, there is marked variation in care depending on the beliefs, attitudes and experience of the GP as to whether it is investigated further and treated, or dismissed as a natural product of ageing. If men are referred to endocrinologists, investigations and management may be more complex than men are expecting and, even amongst specialists, there is variation in treatment decisions for example, variability in the testosterone thresholds for treatment.

Negative connotations of testosterone supplementation by body-builders and the associated increase in aggression prevent some men and GPs from initiating testosterone therapy. Endocrinologists frequently find themselves explaining that it is used in the context of TD to normalise levels, not to enhance them.

There remain concerns for some men, GPs and endocrinologists about the potential side effects of testosterone therapy including prostate cancer which continues to be a barrier to treatment.

## **4. Discussion**

A substantial number of men over the age of 40 have symptoms of TD that have a considerable impact on their daily lives, work, relationships, well-being and sense of worth. These are men who could have a better life experience if TD were recognised, diagnosed and they had access to appropriate, effective treatment. The exact proportion is unknown because of the lack of awareness amongst men and the stigma that accompanies many of the symptoms but is likely to be higher than current estimates. This qualitative study has found that there are multiple barriers to men accessing appropriate investigation and management at each point in the system:

- Men are reluctant to seek help due to embarrassment or lack of knowledge about their symptoms and often wait years before deciding to overcome these barriers and see their GP.
- GPs differ in their knowledge, attitudes and beliefs about TD and so may be highly supportive and proactive in their management, refer to endocrinologists or dismiss the symptoms as part of ageing.
- Endocrinologists have different interpretations of what level of testosterone requires investigation and intervention, and varied beliefs about the potential risks of testosterone therapy with regards to prostate cancer.

## 4.1 Comparison with existing literature

Qualitative literature regarding the experience of men with TD and the barriers to receiving care and support are lacking. A recent systematic qualitative evidence synthesis only identified five studies including 284 men [9]. None directly asked men about barriers to seeking advice and treatment. All studies were from North America with no ethnic minority or other underserved groups included [9].

Previous reports indicated a marked increase in prescriptions for testosterone therapy in the UK with a 90% increase in prescriptions for testosterone preparations over a 10-year period between 2001 and 2010 [10], and testosterone prescribing in the United States (US) increased following publication in 2018 of updated clinical guidelines from the American Urological Association (AUA), and the Endocrine Society [11]. However, despite the increase in prescribing, recent reports in the UK suggest there is still considerable under-treatment of TD [12], which is in keeping with the results of this study. Using published prescribing data from 6781 GP practices significant variation was identified in the number of men aged over 60 who were receiving testosterone therapy prescriptions [12]. Using the expected European prevalence data of 30% of men over the age of 60 with TD, it was found that 7% of practices were treating less than 1% of the expected proportion of men and only 1% were identifying and treating more than 40% of men expected to have TD [12]. Further analysis found that only a small proportion of this variation could be explained by measurable factors such as comorbidities, prescription of PDE5 inhibitors or higher practice rating on the National Patient Survey [13]. This study concluded that most prescribing in primary care is “determined by doctor preference rather than any national guidance” [13]. These two studies concur with the conclusion from this qualitative study that there is variation in care for TD across GPs and endocrinologists. Claims data from the US identified that prescriptions for testosterone therapy had increased most amongst endocrinologists compared with other healthcare providers [11] which reflects the findings from this qualitative study where a small number of specialist GPs were happy to initiate treatment with testosterone therapy, but most referred patients to endocrinologists to initiate treatment and then provided the ongoing care and prescriptions as advised.

The main concern raised about testosterone therapy was whether it increased the risk of prostate cancer. Endocrinologists had differing opinions about this risk. The latest European Association of Urology 2022 guideline pooled the evidence and found no increased risk of prostate cancer in men taking testosterone therapy [2]:

- The most recent meta-analysis of 27 randomised, placebo-controlled, clinical trials of testosterone therapy found no evidence of increased prostate-specific antigen (PSA) after 1 year of treatment and no change in PSA levels nor any increased risk of prostate cancer in men treated for more than one year.

- In three independent registry studies involving more than 1000 men on testosterone therapy, with a median 5-year follow-up, the incidence of prostate cancer was lower than the reported incidence rate in the general population.

- Similar results were obtained from a large cohort study of 10,311 men on testosterone therapy and 28,029 controls with

a median follow-up of 5.3 years.

A recent large randomised placebo-controlled trial of testosterone therapy in 5246 men, whilst designed to investigate cardiovascular (CV) risk, also found no difference in the reported incidence of prostate cancer amongst men on testosterone therapy compared with placebo [14].

The European Association of Urology (EAU) guideline recommends that men should have a prostatic assessment before commencing testosterone therapy and periodic PSA tests during treatment; at 3, 6 and 12 months during the first year of treatment and annually thereafter [2]. According to the guideline, testosterone therapy is contraindicated in people with prostate cancer, but could be used with caution in men who have been treated and have no active prostate cancer and a low risk of recurrence [2]. Known or suspected prostate cancer is a contraindication for testosterone therapy in the Summaries of Product Characteristics (SmPCs) for testosterone therapy products.

Although not a major concern amongst clinicians in this study who were more concerned about the cardiovascular risks resulting from untreated low testosterone levels, the European Urology Association and the European Academy of Andrology recommend the assessment of cardiovascular risk before initiation of testosterone therapy [15, 16]. However, a recent meta-analysis of data from 3431 participants from 9 countries in clinical trials that included individual participant data, found no evidence that testosterone therapy increased short-term to medium-term cardiovascular risks in men with hypogonadism, whilst highlighting that there is a paucity of long-term data [17]. Moreover, a large randomised, placebo-controlled, non-inferiority study in 5246 men with hypogonadism and pre-existing or a high risk of cardiovascular disease, found no increase in the incidence of major cardiac events in men on testosterone-replacement therapy compared with placebo [14].

## 4.2 Strengths and limitations

A major strength of this study is that it captures a broad range of opinions and experiences of GPs, endocrinologists and men who have and have not requested help for symptoms of TD from across the UK. This is the first time to our knowledge that perspectives have been sought from all key stakeholders on the barriers to management of TD.

A limitation of the study is the qualitative nature of the research in that it is reliant on a relatively small sample size so may not be generalisable, but this was necessary in order to be able to explore the reasons behind the views and opinions voiced. Endocrinologists were the only secondary care specialists interviewed, but other specialists who may prescribe testosterone therapy and have alternative perspectives include urologists, sexual medicine specialists and cardiologists.

## 5. Conclusions

This study has identified barriers at every level that are preventing men from being diagnosed with TD and accessing appropriate treatment. This includes a lack of awareness of the symptoms of TD amongst both men and GPs. As a result there are often delays in diagnosis because men do not think to seek



help or advice for non-specific symptoms such as fatigue, low mood or decreased muscle mass, and some GPs do not think to check testosterone levels in men reporting these symptoms. The stigma and embarrassment attached to low testosterone and symptoms such as erectile dysfunction prevent not only men from consulting a GP but also GPs from asking men about sexual symptoms. The taboo is therefore inadvertently reinforced by GPs.

Different attitudes and beliefs amongst GPs and endocrinologists around the definition of TD and at what testosterone level treatment should be initiated means there is continued variation in care, and a lack of consensus amongst endocrinologists across the UK despite attempts by the BSSM in 2017 and EAU in 2019 to provide guidance to standardise care. This lack of clarity may be contributing to GPs referring all symptomatic men with possible low testosterone to endocrinology. It also makes it difficult for GPs to set realistic expectations for men they have referred.

Since the spotlight on the menopause over the past few years, awareness is now shifting towards hormonal therapy for men and there have been reports of a growing number of men asking for their testosterone level to be checked, whether or not they experience symptoms [12]. What is important is that GPs are better equipped to identify and appropriately manage those men who have TD as testosterone therapy is not a panacea for all.

This study has highlighted an educational opportunity to increase the confidence of GPs to identify, investigate and manage straightforward cases of TD, with or without advice from endocrinologists. This would include:

- Raising awareness of the cluster of symptoms of TD.
- The need for total testosterone level to be performed as a fasting blood test between 7am and 11am in the morning, and to be repeated after four weeks to ensure accurate results.
- Assessing free testosterone levels in addition to total testosterone to confirm suitability for treatment with testosterone therapy.
- Optimising treatment of co-morbidities including type 2 diabetes.
- Addressing modifiable risk factors such as obesity.
- Understanding that testosterone therapy has a place for some individuals alongside these measures.

## AVAILABILITY OF DATA AND MATERIALS

The transcripts from interviews analyzed for the current study are not publicly available because consent to share aggregated data and unattributed extracted quotes was obtained from participants and is included in this manuscript, but consent to share was not sought for individual data sets (interview transcripts) because of the need to protect the identities of participants.

## AUTHOR CONTRIBUTIONS

JD and AC—were involved in the study design, reviewed the analysis and the results and reviewed drafts of this manuscript. Both authors contributed to editorial changes in the manuscript. Both authors read and approved the final

manuscript.

## ETHICS APPROVAL AND CONSENT TO PARTICIPATE

This study was conducted in accordance with the guidelines of the Declaration of Helsinki. This study was submitted to Reading Independent Ethics Committee, an independent research ethics committee for review in December 2021. Having reviewed the study outline and interview guides, they confirmed that no formal ethical review was required for this research. All men, GPs and endocrinologists gave informed consent to participate in the study.

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## CONFLICT OF INTEREST

The authors declare no conflict of interest.

## REFERENCES

- [1] Hackett G, Kirby M, Rees RW, Jones TH, Muneer A, Livingston M, *et al.* The British society for sexual medicine guidelines on male adult testosterone deficiency, with statements for practice. *The World Journal of Men's Health.* 2023; 41: 508–537.
- [2] Salonia A, Bettocchi C, Carvalho J, Corona G, Jones TH, Kadioğlu A, *et al.*; European Association of Urology. EAU guidelines on sexual and reproductive health. 2022. Available at: [https://d56bochluxqz.cloudfront.net/documents/full-guideline/EAU-Guidelines-on-Sexual-and-Reproductive-Health-2022\\_2022-03-29-084141\\_megw.pdf](https://d56bochluxqz.cloudfront.net/documents/full-guideline/EAU-Guidelines-on-Sexual-and-Reproductive-Health-2022_2022-03-29-084141_megw.pdf) (Accessed: 13 January 2023).
- [3] Mulligan T, Frick MF, Zuraw QC, Stenhagen A, McWhirter C. Prevalence of hypogonadism in males aged at least 45 years: the HIM study. *International Journal Clinical Practice.* 2006; 60: 762–769.
- [4] Wiechno PJ, Kowalska M, Kucharz J, Sadowska M, Michalski W, Poniatowska G, *et al.* Dynamics of hormonal disorders following unilateral orchiectomy for a testicular tumor. *Medical Oncology.* 2017; 34: 84.
- [5] Grossmann M, Matsumoto AM. A perspective on middle-aged and older men with functional hypogonadism: focus on holistic management. *The Journal of Clinical Endocrinology & Metabolism.* 2017; 102: 1067–1075.
- [6] Cervoni E. NHS discrimination of testosterone deficiency syndrome. *Trends in Urology and Men's Health.* 2020; 11: 23–26.
- [7] Glaser BG, Strauss AL. The discovery of grounded theory. In Glaser BG, Strauss AL (eds.) *The discovery of grounded theory* (pp. 1–18). 1st edn. Routledge: New York. 2017.
- [8] Hackett G, Kirby M, Edwards D, Jones TH, Rees J, Muneer A. UK policy

- statements on testosterone deficiency. *International Journal of Clinical Practice*. 2017; 71: e12901.
- [9] Aceves-Martins M, Quinton R, Brazzelli M, Cruickshank M, Manson P, Hudson J, *et al*. Identifying the outcomes important to men with hypogonadism: a qualitative evidence synthesis. *Andrology*. 2022; 10: 625–641.
- [10] Gan EH, Pattman S, Pearce SHS, Quinton R. A UK epidemic of testosterone prescribing 2001–2010. *Clinical Endocrinology*. 2013; 79: 564–570.
- [11] Sellke N, Omil-Lima D, Sun HH, Tay K, Rhodes S, Loeb A, *et al*. Trends in testosterone prescription during the release of society guidelines. *International Journal of Impotence Research*. 2023; 1–5.
- [12] Stedman M, Livingston M, Albanese M, Hackett G, Heald AH. Hypogonadism is not being sufficiently recognised in 99% of general practices/family doctor surgeries. *International Journal of Clinical Practice*. 2020; 74: e13445.
- [13] Heald AH, Stedman M, Whyte M, Livingston M, Albanese M, Ramachandran S, *et al*. Lessons learnt from the variation across 6741 family/general practices in England in the use of treatments for hypogonadism. *Clinical Endocrinology*. 2021; 94: 827–836.
- [14] Lincoff AM, Bhasin S, Flevaris P, Mitchell LM, Basaria S, Boden WE, *et al*. Cardiovascular safety of testosterone-replacement therapy. *New England Journal of Medicine*. 2023; 389: 107–117.
- [15] Dohle G, Arver S, Bettocchi C, Jones T, Kliesch S; European Association of Urology. EAU guidelines on male hypogonadism. 2019. Available at: <https://d56bochluxqz.cloudfront.net/media/EAU-Guidelines-on-Male-Hypogonadism-2019v2.pdf> (Accessed: 22 September 2023).
- [16] Corona G, Goulis DG, Huhtaniemi I, Zitzmann M, Toppari J, Forti G, *et al*. European academy of andrology (EAA) guidelines on investigation, treatment and monitoring of functional hypogonadism in males. *Andrology*. 2020; 8: 970–987.
- [17] Hudson J, Cruickshank M, Quinton R, Aucott L, Aceves-Martins M, *et al*. Adverse cardiovascular events and mortality in men during testosterone treatment: an individual patient and aggregate data meta-analysis. *The Lancet. Healthy Longevity*. 2022; 3: e381–e393.

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