

# What happens to men who say 'no' to prostate cancer treatment

by Jill Margo in AFR on 24 May 2019

Choosing not to have treatment for prostate cancer has complex consequences.

When men say “no” to treatment for prostate cancer, they don’t walk away feeling unburdened and free of concern. They’ve made a difficult decision and, as the diagnosis stays with them, they live with complex consequences.

These can be profound and can affect their psychological wellbeing, family, employment, identity and life choices, according to the first study in the world to analyse the hidden experience of men who resisted recommended treatment.

These men were Australian, well educated, economically successful with high health literacy and the means and capacity to challenge medical advice. They hoped they were doing the right thing, but not all were correct. Some still have doubts and others say the sense that they were playing with fire persisted for many years.

For the study, published in the journal BMJ Open, researchers spent hours interviewing the 11 men to try to understand if and how they came to terms with their disease.

All had biopsy-confirmed prostate cancer and all initially declined surgery or radiation, devising their own strategies instead. Most felt pressured by their urologist to have surgery and suspected there was a financial motive in the mix.

In a vulnerable state, having just received a diagnosis, several were told they would soon die without treatment – a prognosis that did not eventuate.

At the time of the interviews, the men were aged between 59 and 78. They had been diagnosed at various points during the past 20 years.

Several felt they had to do something and pursued expensive alternative therapies that had little evidence to support them.

Professor Kirsten McCaffery’s study Professor Kirsten McCaffery’s study explores the hidden experiences of men who have been recommended but decline surgery.

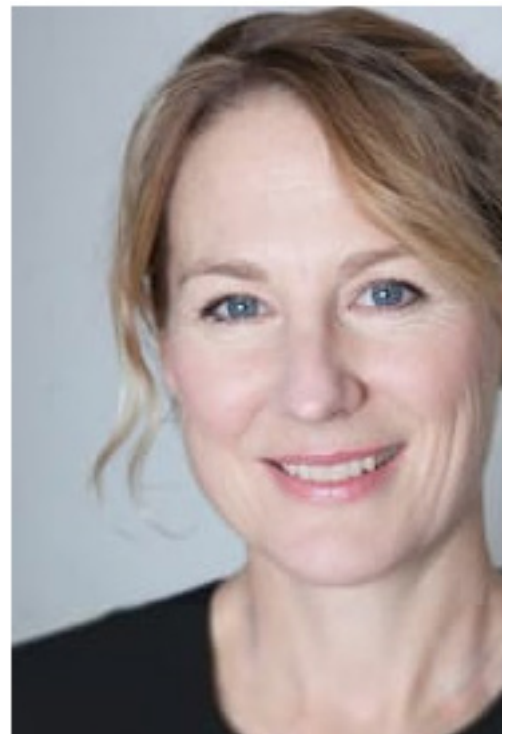
Feeling frightened

While strong enough to make independent decisions and challenge the medical advice they were given, many felt threatened and frightened by their impending death and began to finalise their affairs. Two got divorced.

In one case study a man called Jim, who was diagnosed at 54, said it took him ages to get his head around it. His encounter with the urologist was off-putting, especially as he was booked for immediate surgery without discussing alternatives.

So, he began an extensive investigation of the options, gathering information from multiple sources and having scans. At the time of the interview, eight years had passed since his diagnosis and he continues to monitor his cancer closely.

Although he’s happy with his decision not to have active treatment, there has been a cost. His wife could not accept his decision and this contributed to a debilitating divorce. For him, the psychological impact of resisting surgery is ongoing, it is “a mental thing that you have to deal with every day ... it plays on your mind”.



Others concurred, saying it had been an intensely psychological experience with high anxiety and doubt.

In the aftermath of diagnosis, some men extracted themselves from business partnerships leading to loss of income and a change in financial circumstances. A few left work entirely or modified their employment to make time to research and focus on their health and pursue alternative treatments overseas.

One was Bob, who - on being diagnosed at 69 - was told he would be dead in three years if he did not have his prostate removed immediately.

“Dead in three years! That’s all I could think of,” he said. When he asked for a second opinion, he was referred to his urologist’s partner, which prompted him to look for alternative treatments.

For the next few years he read nothing but medical books, consulted interstate and internationally and went abroad for scans.

He withdrew from part of his business, would wake at 3am, and felt alone because he didn't have a doctor he believed in.

At the time of his interview, seven years had passed since his diagnosis and his cancer had not changed in any way. But he'd changed: sleeplessness was still there and so was the doubt.

#### Side effects

Some men were more focused on the side effects of treatment rather than death. As one put it, "I was very worried about the possibility of long-term incontinence. The idea of having to wear pads in my underpants for possibly the rest of my life was not attractive."

The study, which included men from around the country, was led by Professor Kirsten McCaffery, director of Sydney Health Literacy Lab, and one of the lead investigators at Wiser Healthcare, University of Sydney.

She says the accounts given by these men usually remain hidden partly because it is difficult to find men who feel they may have been over-diagnosed and who then decided not to be treated.

The treatment was declared a success and he was sent home. But a year later he was in trouble.

In contrast to most cancer patients, she says these men did not perceive their diagnosis as life-saving or life-affirming.

Some had their PSA (blood tested for prostate cancer) without their knowledge. They felt uninformed about their options and unsupported throughout the process of deciding what to do. Ultimately, this left them feeling disillusioned and distrustful towards the medical profession.

But for doctors on the other side of the desk, the correct decision is not always crystal clear. To reduce risk and be safe, they sometimes suggest treatment, even if it might be over-treatment.

Their difficulty predicting which cancers will not progress is reflected in current estimates drawn from the largest studies available, which say 41 per cent of prostate cancers are not destined to cause illness or death.

#### Uncertainty and angst

Of the 11 men, two went on to have surgery and one progressed to radiation treatment.

In their interviews, these men described significant uncertainty and angst about their decision to delay. They had a sophisticated understanding and recognised they would never know if they had made the right decision. Their guilt, questioning and uncertainty was significant and unresolvable.

One was Peter, who was diagnosed at 56. While he had resisted having a biopsy for many years, he chose to have ultrasound and a new laser treatment in New York, which cost \$30,000.

If I die in the next five years of metastasis then I'll know I waited too long.

— One of the men who decided on surgery, who was also a medical doctor

The treatment was declared a success and he was sent home. But a year later he was in trouble. A full-body CT scan revealed potential secondary cancer in his hip. As the laser treatment had ruled out the surgical option, he struggled through hormone treatment and aggressive radiation.

Peter described the process as a rollercoaster. At the time of interview, it had been two years since his radiation therapy and he still had side effects including some impotence and rectal bleeding.

Reducing his working hours had a big impact and he said he suffered from anxiety attacks so intense sometimes he is almost petrified with fear. He accepts that a biopsy earlier on would have changed his journey and that he probably should have had it.

#### Questioning decisions

One of the men who decided on surgery was a medical doctor and fully informed of his options. He made the decision after receiving a blood result showing a high level of the marker for prostate cancer.

Using frank language, he described how he couldn't really tell if he had been over-diagnosed or whether the diagnosis and surgery saved his life.

"There's a part of me that wonders did I f--- myself up because I waited 3½ years or, did I f--- myself up because I had the cleanout ... I'll never know.

"If I die in the next five years of metastasis then I'll know I waited too long, if I die of something else, I won't know if this never would've spread anyway, or they saved my life."

He had spent much time questioning and reviewing the decisions he'd made. "I had lost a considerable amount of weight, I went to see the urologist and he didn't say. 'Because you waited' but it was implied, that maybe if I had addressed this 3½ years ago ..."

As the years passed, others reframed their experiences positively.

"I played that game for about three years, running around the world, then I realised nothing was happening, I was fine," said one.

I've known for five and a half years that I've got cancer in me, and I'm still living.

Another said as time went on and he gained more knowledge and information: "Knowing how rigged the medical profession operates in this particular sphere his anxiety had sort of gone down."

#### Changing practices

At the time of the interviews, eight of the men were suffering no related physical problems. Several reflected on their increasing awareness that their cancer had not progressed, may never do so and might not be the life-threatening scenario that had been presented to them.

Some questioned whether alternative healing had helped or whether the outcome would have been the same regardless.

"I've known for 5½ years that I've got cancer in me, and I'm still living, walking around, no side effects, no nothing, perhaps I will be OK," said one.

Professor McCaffery says policies and practices have changed over the past 20 years, and surveillance programs that are now recommended for men with low-risk disease were not a common option when some men in this study were first diagnosed.

"But still, not enough men are informed of the pros and cons by their GP before they take a blood test. Once diagnosed, they continue to be rushed into decisions that need careful consideration at all stages of the journey.

"This has profound and life-long consequences for them and their families and has to change."

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