

Stories of overdiagnosis: men's experiences of choosing not to have surgery for prostate cancer

Brooke Nickel, Kirsten McCaffery,
Jolyn Hersch, Ray Moynihan,
Alex Barratt



@wiserhealthcare



THE UNIVERSITY OF
SYDNEY



**WISER
HEALTHCARE**
A RESEARCH COLLABORATION FOR REDUCING
OVERDIAGNOSIS AND OVERTREATMENT



BACKGROUND

- Overdiagnosis of prostate cancer (PCa) is widely accepted
 - Estimates range from 1.7-67% (Loeb, 2014)
 - High prevalence of incidental PCa at autopsy, estimated at 59% by age >79 years (Bell, 2015)

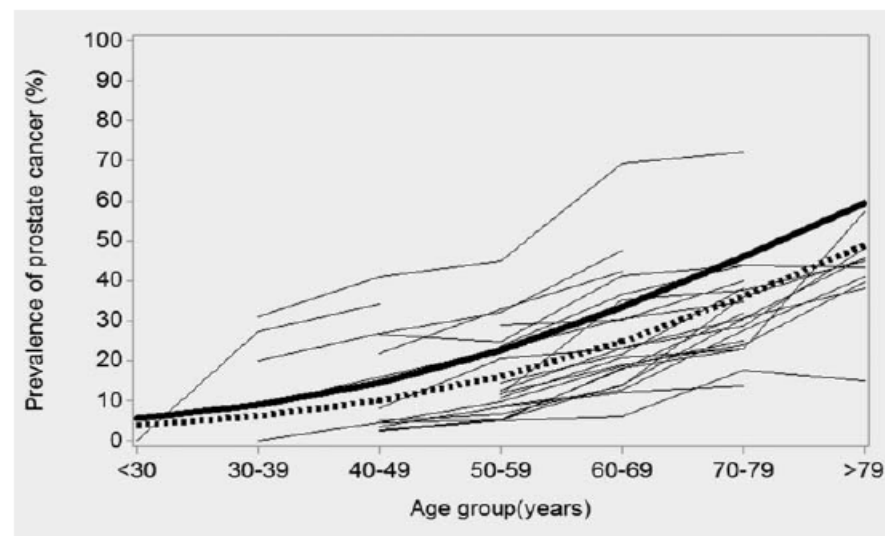
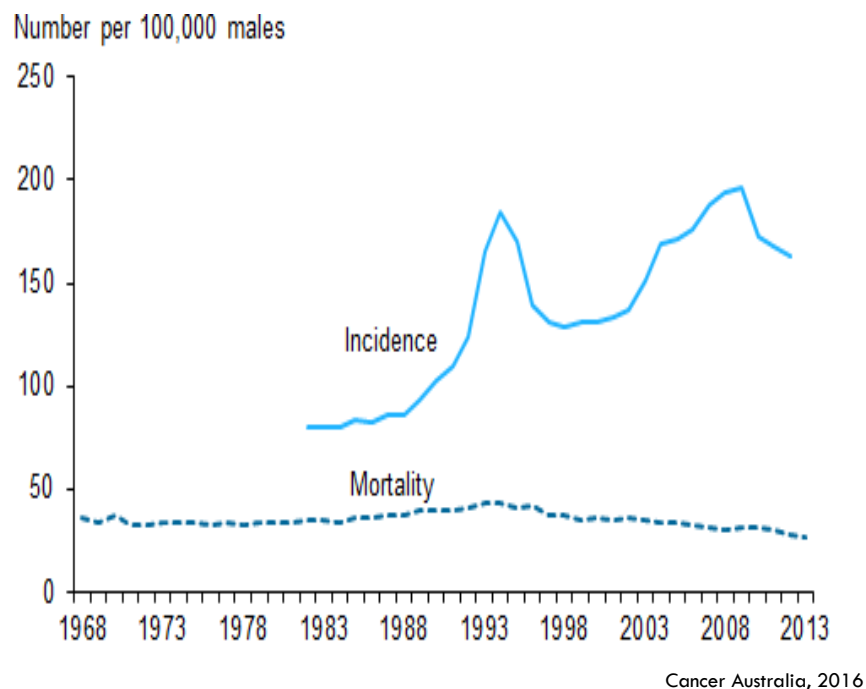
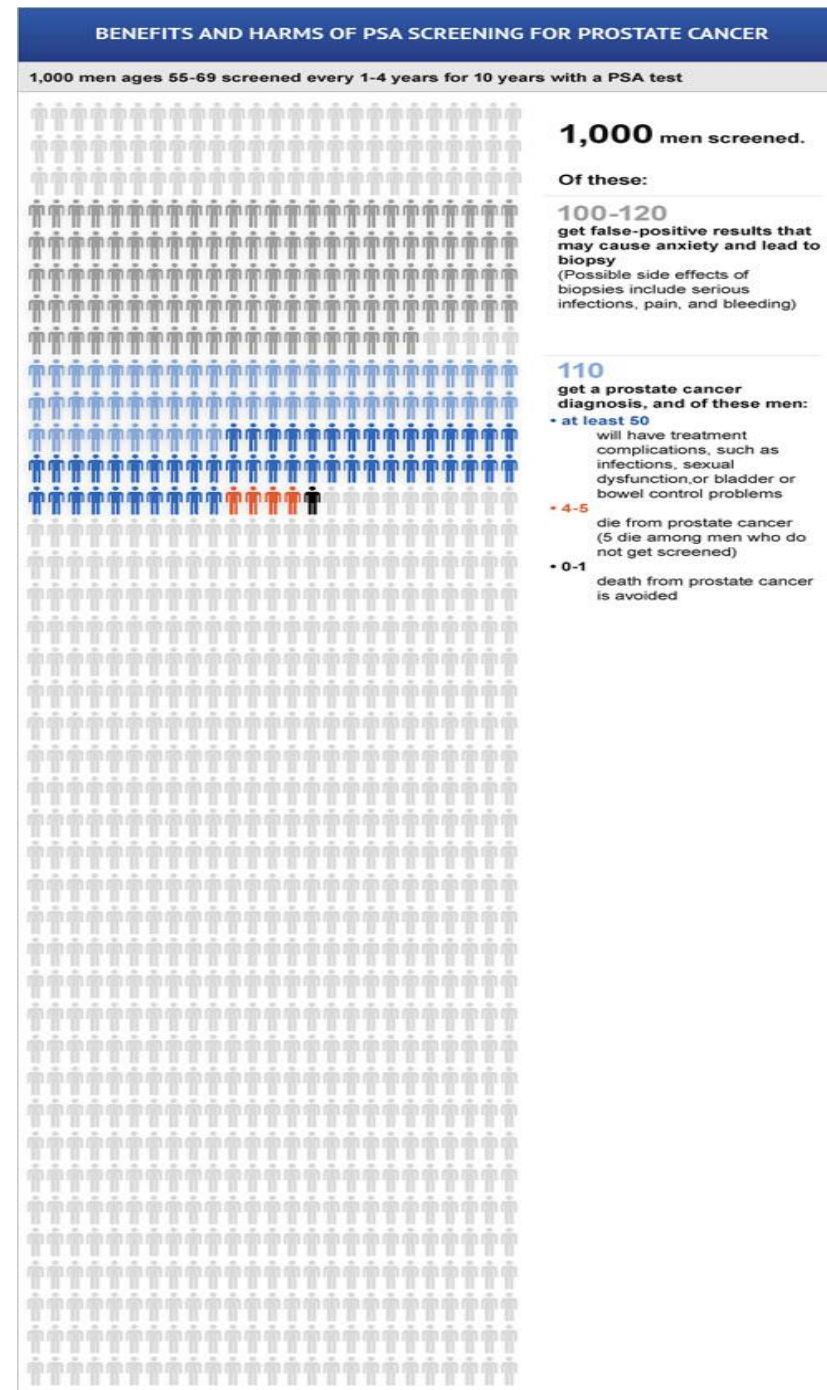


Figure 3. Decade-specific prevalence of: (i) incidental prostate cancer from studies and (ii) mean prevalence from models before and after adjustment for use of Gleason score 294 × 188 mm (100 × 100 DPI).

Bell, 2015

BACKGROUND

- Despite concerns about the harms of PSA screening and recommendations against it, a significant number of men continue to be screened (Tang 2016, Drazer 2012)
- Majority men diagnosed with low-risk, clinically localised PCa undergo initial treatment (Thompson 2003, Schroder 2009, Cooperberg 2007, Andriole 2009)
- Active surveillance management approach has recently become more accepted as a way to mitigate the effects of overtreatment



AIM & METHOD

AIM:

To examine the narratives of men diagnosed with PCa who went against clinical recommendations for surgery and remain healthy today

METHOD:

- Qualitative study using open-ended face-to-face interviews
- Participants were recruited via online information and support groups for men with PCa seeking non-surgical management, and through snowball techniques
- Interviews were audio-recorded and transcribed verbatim, and thematic analysis was used to analyse the data

DEMOGRAPHIC CHARACTERISTICS

Characteristic	Number of men (n=11)
Current age	
≤60	1
61-70	4
70+	6
Age at diagnosis	
≤50	1
51-60	5
61-70	3
70+	2
Education	
College diploma/trade certificate or below	2
Bachelors degree or above	9
Current working status	
Working full-time	4
Working part-time	4
Retired	3

CLINICAL CHARACTERISTICS

- All men had received a biopsy confirmed diagnosis of PCa
- Self-reported PSA levels at the time of diagnosis were between 2-13 and Gleason scores were between 6-8
- Diagnosed <1-20 years ago (mean=7.7 years)
- All men were strongly recommended to follow surgical management
- All men initially elected not to have surgery and instead devised their own less invasive management plan
 - 2 men went on to have surgery after a number of years for different reasons

RESULTS

Key Themes	Example(s)
Unaware of the initial PSA test/uninformed about its consequences	Routine test completed due to age
Feeling rushed and pressured into prostatectomy once diagnosis was confirmed	Surgery booked the week after diagnosis
Significant negative impact on work, quality of life, and relationships	Quitting work, marriage break-up
Persistent anxiety	Night waking 7 years post-diagnosis
Deep cynicism towards conventional medicine and associated financial conflicts of interest	Belief that surgical recommendation was for financial gain
Travelling overseas for expensive alternative tests and treatments	Hyperthermia treatment in Europe

RESULTS

Key Themes	Example(s)
Unaware of the initial PSA test/uninformed about its consequences	Routine test completed due to age
Feeling rushed and pressured into prostatectomy once diagnosis was confirmed	Surgery booked the week after diagnosis
Significant negative impact on work, quality of life, and relationships	Quitting work, marriage break-up
Persistent anxiety	Night waking 7 years post-diagnosis
Deep cynicism towards conventional medicine and associated financial conflicts of interest	Belief that surgical recommendation was for financial gain
Travelling overseas for expensive alternative tests and treatments	Hyperthermia treatment in Europe

“I had no idea what a PSA test was. The doctor said “it’s time” and I went along with it.”

(ID2, 76yrs, age dx: 69, PSA: 1.6)

“I wouldn’t even have known what a prostate was about or I wouldn’t even have thought about it. I never had PSA tests until I got this [UTI].”

(ID11, 71yrs, age dx: 56, PSA: 2.0)

RESULTS

Key Themes	Example(s)
Unaware of the initial PSA test/uninformed about its consequences	Routine test completed due to age
Feeling rushed and pressured into prostatectomy once diagnosis was confirmed	Surgery booked the week after diagnosis
Significant negative impact on work, quality of life, and relationships	Quitting work, marriage break-up
Persistent anxiety	Night waking 7 years post-diagnosis
Deep cynicism towards conventional medicine and associated financial conflicts of interest	Belief that surgical recommendation was for financial gain
Travelling overseas for expensive alternative tests and treatments	Hyperthermia treatment in Europe

“I was immediately thinking, ‘You’re in a real hurry to get me on the table’... he was booking me in till, I can still remember, June the 10th...looked at this calendar and said, ‘I can fit you in then.’”

(ID4, 65yrs, age dx: 60, PSA: 3)

RESULTS

Key Themes	Example(s)
Unaware of the initial PSA test/uninformed about its consequences	Routine test completed due to age
Feeling rushed and pressured into prostatectomy once diagnosis was confirmed	Surgery booked the week after diagnosis
Significant negative impact on work, quality of life, and relationships	Quitting work, marriage break-up
Persistent anxiety	Night waking 7 years post-diagnosis
Deep cynicism towards conventional medicine and associated financial conflicts of interest	Belief that surgical recommendation was for financial gain
Travelling overseas for expensive alternative tests and treatments	Hyperthermia treatment in Europe

“I decided to walk out of my marriage... I decided to walk out of my business... I decided to walk out of my partnership in China...”

(ID5, 63yrs, age dx: 43, PSA: 6.3)

“It caused a divorce, um...my, um, my wife... she was, um, adamant that I should have a prostatectomy... that's been quite debilitating, um, because my kids are involved and everything like that.”

(ID9, 62 yrs, age dx: 54, PSA: 5.4)

RESULTS

Key Themes	Example(s)
Unaware of the initial PSA test/uninformed about its consequences	Routine test completed due to age
Feeling rushed and pressured into prostatectomy once diagnosis was confirmed	Surgery booked the week after diagnosis
Significant negative impact on work, quality of life, and relationships	Quitting work, marriage break-up
Persistent anxiety	Night waking 7 years post-diagnosis
Deep cynicism towards conventional medicine and associated financial conflicts of interest	Belief that surgical recommendation was for financial gain
Travelling overseas for expensive alternative tests and treatments	Hyperthermia treatment in Europe

“3am in the morning when you wake up and you start thinking of how little of your life you might have left.”

(ID2, 76 yrs, age dx: 69, PSA 1.6)

“It’s a mental thing that you have to deal with every day, ah, but you have to, but, you know, you have to stay positive and, um, and, um, keep active and ah, yeah, it plays on your mind.”

(ID9, 62 yrs, age dx: 54, PSA: 5.4)

RESULTS

Key Themes	Example(s)
Unaware of the initial PSA test/uninformed about its consequences	Routine test completed due to age
Feeling rushed and pressured into prostatectomy once diagnosis was confirmed	Surgery booked the week after diagnosis
Significant negative impact on work, quality of life, and relationships	Quitting work, marriage break-up
Persistent anxiety	Night waking 7 years post-diagnosis
Deep cynicism towards conventional medicine and associated financial conflicts of interest	Belief that surgical recommendation was for financial gain
Travelling overseas for expensive alternative tests and treatments	Hyperthermia treatment in Europe

“It just looked like a money making ah, experience for me. Ah the guy was very unhelpful, he was rude, and, um, I didn't like it at all... I have a profound distrust. The way I've been treated by urologists and my experience in the whole thing.”

(ID9, 62 yrs, age dx: 54, PSA: 5.4)

RESULTS

Key Themes	Example(s)
Unaware of the initial PSA test/uninformed about its consequences	Routine test completed due to age
Feeling rushed and pressured into prostatectomy once diagnosis was confirmed	Surgery booked the week after diagnosis
Significant negative impact on work, quality of life, and relationships	Quitting work, marriage break-up
Persistent anxiety	Night waking 7 years post-diagnosis
Deep cynicism towards conventional medicine and associated financial conflicts of interest	Belief that surgical recommendation was for financial gain
Travelling overseas for expensive alternative tests and treatments	Hyperthermia treatment in Europe

“Within a week I was on a plane to New York... Um, and I told [the radiologist] I was going to Germany to have hyperthermia and his words were, “It’ll do you no harm”. And so within 10 days I was sitting in the chair in Germany.”

(ID4, 65yrs, age dx: 60, PSA: 3)

DISCUSSION

- The majority of men were uninformed about the PSA test and its consequences
- PCa diagnosis had a dramatic impact on the men's lives
- 9 of 11 men who have still not had surgery remained healthy and PCa has not progressed
- Most men pursued some kind of alternative treatment
 - Uncritical support for expensive alternative (less aggressive) unproven therapies
 - Potential challenge of active surveillance
- Deep cynicism by several men about conventional medicine and of potential financial COI among urologists and their recommendations for surgery
 - High SES of men – confidence to challenge their clinicians

CONCLUSION



- Overdiagnosis of PCa remains a problem as men continue to undergo PSA testing uninformed about its consequences
- Men who choose not to have surgery still feel that they need to do ‘something’ about their PCa diagnosis and continue to live with the impact of being diagnosed with cancer

ACKNOWLEDGEMENTS

The men who volunteered to take part in the study

Wiser Healthcare, University of Sydney



Kirsten McCaffery, Jolyn Hersch, Alex Barratt, Ray Moynihan

Thank you

brooke.nickel@sydney.edu.au



[@wiserhealthcare](https://twitter.com/wiserhealthcare)



THE UNIVERSITY OF
SYDNEY