Decision regret in men treated with curative intent for prostate cancer: results from the Life After Prostate Cancer Diagnosis study


Poster Wagland et al: The quality of treatment decision-making amongst men with prostate cancer: preliminary qualitative findings from the Life After Prostate Cancer Diagnosis (LAPCD) study
Incidence and survival

- Prostate cancer (PCa) is the commonest cancer in men in the United Kingdom (UK)
  - Stage 1: 30% of cases almost everyone will survive their cancer for 5 years +
  - Stage 2: 20% of cases almost 95% will survive their cancer for 5 years +
  - Stage 3: 19% of cases

Cancer Research UK
Treatment options for stage 1 & 2 prostate cancer

• Active surveillance (no treatment)
• Surgery
• Radiotherapy
• May go on to receive androgen-deprivation therapy - ADT (hormones)

Treatment options for stage 3 (locally advanced) prostate cancer

• Try and cure the cancer - often with multiple radical treatments
• Accept incurability and go to Watchful Waiting (no treatment)
Patient Reported Outcomes

- Urinary
- Bowel
- Sexual
- Masculinity
- Anxiety
Treatment decision making

Shared decision making is encouraged

How can I know what’s best?
Study Design

- Identified: Cancer Registration
- 18-42 months post diagnosis
- Cohort 1:
  - survey twice (12 months)
  - subset interviewed
- Cohort 2: survey once (England)
- Patient Reported Outcome Measures (PROMs)
- Data linkage

Downing et al. 2016, BMJ Open;6(12).
Study Design

- Cohort 1, Time 1, England only
- PROMs
  - The Decision Regret Scale  
  - Item on decision participation
    “Do you think your views were taken into account when the team of doctors and nurses caring for you were discussing which treatment you should have?”
- EPIC-26  
    - Five subscales (urinary x 2, bowel, sexual, hormonal)
Preliminary results

30,465 men participated (60%)

23,001 men were stage 1-3

17,292 (75.2%) completed the Decision Regret Scale
Decision regret

- No regret: 6,184 men (35.8%)
- Low regret: 5,523 men (31.9%)
- High regret: 5,585 men (32.3%)
Decision involvement & regret

Were your views taken into account?
- Yes, definitely
- Yes, to some extent
- No
- Didn't know it was being discussed
- Not sure/can't remember

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No decision regret | Low decision regret | High decision regret

0% | 0% | 0%
10% | 10% | 10%
20% | 20% | 20%
30% | 30% | 30%
40% | 40% | 40%
50% | 50% | 50%
60% | 60% | 60%
70% | 70% | 70%
80% | 80% | 80%
90% | 90% | 90%
100% | 100% | 100%
Least regret
• surgery alone
• brachytherapy alone
• monitoring (no treatment)
Decision regret & PROMs

- Moderate or big urinary problem
- Moderate or big bowel problem
- Moderate or big sexual problem

- No regret
- Low regret
- High regret

- No, moderate/big problem
- Yes, moderate or big problem
Conclusions

- 73% of men reported their views were definitely taken into account
- Decision regret was experienced by >60% of men
- We don’t know if they would have regretted a different treatment choice

- Less regret is associated with
  - Reporting being involved in the decision making process
  - Brachytherapy, surgery alone and monitoring

- Regret is associated, to an extent, with the level of ‘problem’ experienced
• Need to undertake more complex analysis/modelling
  • Include sociodemographic variables (e.g. age)
  • Include clinical variables (e.g. co-morbidity)

• Need to separate stage 1 & 2 from stage 3 to check if results remain constant

• Include data from the devolved nations

We would like to provide men and clinical teams with knowledge of specific personal issues for the men to consider when making their treatment choice, based on the findings of this population based study.
Thanks to

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The LAPCD Clinical & Scientific Advisory Group
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