Factors influencing the quality of treatment decision-making amongst men diagnosed with localised and locally advanced prostate cancer: findings from a UK-wide mixed methods study

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Introduction

Men diagnosed with localised and locally advanced prostate cancer (PCa) are frequently offered a range of possible treatment options, including surgery, radiotherapy, brachytherapy, hormone therapy or combinations. Potential side effects, including sexual, urinary and bowel dysfunction, hot flushes, and weight gain, can vary by treatment type. Men also have the option of going on active surveillance or watchful waiting which avoids/delays active treatment. This study, part of a UK-wide, patient-reported outcome study entitled Life After Prostate Cancer Diagnosis, explored the treatment decision-making (TDM) experience of men diagnosed with Stage 1-111 PCa. [1]

Aim

To explore reported TDM experiences of men with localised and locally advanced PCa.

Methods

Mixed-methods study incorporating a cross-sectional postal survey of men 18-42 months post-diagnosis and semi-structured interviews with a subsample (n=97, Stage 1-111). Interview data were analysed using Framework approach.

Findings

Within the context of TDM, 'drivers' included men's preferences about their level of involvement in decision-making or whether to delegate responsibility to clinicians, the relative intrusiveness of treatment or their desire for surgical excision ('cut it out'), and work, personal and social life priorities.

Treatment 'drivers': Preference for TDM responsibility

"The doctors have had control of [treatment decision]. I've just done what I'm told. I don't want the responsibility. .. I did what I was told. I didn't want to have any control, I didn't know enough about it. It wasn't up to me." (68 years, Radiotherapy and Hormone therapy)

Treatment 'drivers': Patient priorities

"I just immediately said to him right, get it out, I do not want this inside of me. Gave me options of what treatment could be done, and even leave it… he said nothing may happen, and you could take it to your grave.. or we can do radiotherapy ….and I just said no, get it out."
(54 years Open Prostatectomy)

Categories	Themes
Drivers	Preference for involvement in TDM
	Priorities for work/ lifestyle
	Treatment preferences or 'let sleeping dogs lie'
	Previous experience of friends and family
	Perception of certain treatments as 'intrusive'/ 'invasive'
Facilitators	Information regarding treatment options
	Information regarding treatment side effects (severity/prevalence
	Treatment Decision Aids (TDAs)
	Involvement of partners
	Access to lived experience of previously treated men
	Unrushed environment

Treatment 'facilitators': Availability of information

"I was taken through lots and lots of detail, leaflets and lots and lots of information so that I could make my own decision as to what course of action to take, which I did.'

(53 years, Robotic Prostatectomy)

TDM 'facilitators' were mechanisms such as shared decision-making, communication and information sharing between patients, spouses and clinicians, that help clinicians enact, but also sometimes to challenge drivers. Drivers and facilitators can conflict, challenging patient empowerment.

Men frequently undertook greater TDM responsibility than they desired, with no clinical recommendations to guide decisions; others reported receiving conflicting clinical recommendations from different clinicians involved in their care. Information on potential side effects was often reported as inadequate. Unchallenged preferences, absence of clinical recommendations and inadequate preparation for side effects sometimes led to decision regret.

Conflict between drivers and facilitators: Men unable to exercise preference to delegate TDM responsibility

"The problem is I've asked them [clinicians] about treatments and the best treatment and they haven't been able to give me an answer. … They say it's up to me to decide which treatment I want. Unfortunately, because I'm not qualified in that area I can't give an opinion on that, so I'm a bit in limbo [about] which is the best treatment. … I'm very, very depressed about it."

(67 years, stage 1, Active Surveillance)

Conclusions

TDM should involve men exercising preferences and priorities in discussion with clinicians. Men are not empowered when required to take more TDM responsibility than desired or when their potentially inappropriate preferences are unchallenged. Clinicians should ensure patients do not receive conflicting recommendations.

References:

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