

‘Very difficult for an ordinary guy’: 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. Patient Education and Counselling.

What did we already know?

The treatment decision-making (TDM) process for men diagnosed with localised or locally advanced PCa is particularly difficult, as there are often several equally effective treatment options available, each of which have associated side effects that can have long-term impact upon men’s quality of life. These side effects can include sexual and urinary dysfunction following surgery, bowel dysfunction, loss of libido and urinary irritations following radiotherapy, and gynecomastia, mood disturbances, weight gain, penile shrinkage, loss of libido and hot flushes following hormone therapy. Active surveillance avoids or delays active treatment and associated side effects, but men can nevertheless become anxious about not treating the cancer and worry it will spread.

What did we do?

Men alive 18–42 months following prostate cancer diagnosis in participating Trusts were identified through population-based cancer registries in England, Wales, Scotland and Northern Ireland, and mailed surveys from their treating Trust/Board. Respondents indicated on the survey their willingness to be contacted and invited for interview. The survey asked respondents whether they thought their views were taken into account when their doctors and nurses were discussing which treatment they should have. Telephone interviews were then conducted with a selected sample of respondents who had received a range of treatments to further explore their treatment decisions.

What did we find?

Most men who completed the survey (68.8%) indicated their views had ‘definitely’ been taken into account during the TDM process. Fewer men (17.8%) indicated their views were ‘to some extent’ taken into account, suggesting they were not fully involved with the TDM process. Very few (3.3%) indicated their views were ‘not taken into account’. Interviews found men were often unhappy about the TDM process because they did not receive enough information about various treatment options or possible side effects, or they felt rushed into making a decision or were expected to take more responsibility for decision making than they desired. Men often had personal preferences for specific treatment options associated with priorities around work, personal and social lives, and had perceptions of how ‘intrusive’ some treatments would be. Others overwhelmingly desired surgery to ‘cut out’ the cancer. What helped a good TDM process was good communication between men, clinicians and their partners, accessibility to tailored, easily understood information about what to expect during and following treatment, and honest recommendations about best treatment when this was requested. Unchallenged preferences, absence of or conflicting recommendations and inadequate preparation for treatment side-effects sometimes led to decision regret.

How will these results be used?

Men should be informed of exactly which appropriate treatment options are available and why others are not, and the prevalence and potential severity of associated side effects. Use of patient decision aids should be encouraged. Some men desire greater direction from clinicians about the most appropriate treatments, and where possible this should be respected. Expecting men to take greater TDM responsibility than desired can for some men inhibit rather than facilitate patient empowerment. All clinicians involved in a patient’s care should be cognizant of each other’s views

and ensure patients do not receive conflicting recommendations. Men with firm treatment preferences should be encouraged to discuss these with clinicians to prevent potential subsequent decision regret.