

Informational Needs During Active Surveillance for Prostate Cancer: A Qualitative Study

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Background Active surveillance (AS) is increasingly utilized for the management of favorable-risk prostate cancer. Our objective was to understand the informational needs of men on AS from the perspective of prostate cancer patients and providers.

Methods We conducted seven focus groups with 37 men on AS in two different clinical settings, and 24 semi-structured interviews with physicians caring for men on AS. Patient focus group questions covered current patient information-seeking practices, perceptions of available information, what men would like to know, and how they would like to be informed about AS. Interview questions with physicians included perceptions of current informational resources for patients on AS and recommendations for additional resources. Transcripts were analyzed using applied thematic analysis, and themes were organized using descriptive matrix analyses.

Results A minority of patients felt that in-person visits with their physician were sufficient to receive information about AS, while others felt confused and uncomfortable with their own lack of knowledge about monitoring protocols. All patients wanted more information about disease prognosis, testing options, and/or lifestyle modification. Physicians differed on whether they felt that in-person visits provided sufficient time and depth to cover the necessary topics, and whether they refer their AS patients to any external sources. A minority of physicians had no idea where their patients get information. Both patients and physicians expressed concerns about the quality of information on the Internet about prostate cancer in general and AS.

Conclusions These results are useful to inform the design of educational materials or decision support tools for AS. Suggested topics for additional information include general information about prostate cancer and treatment options, testing protocols during AS, and lifestyle recommendations.

Conflict of Interest Statement The authors report no relevant conflicts of interest.

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