Editorial Commentary on Expectant Management in Genitourinary Malignancies (Prostate, Bladder, Kidney)

The need for research methodology to improve acceptability of long-term surveillance for cancer

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The increasing use of surveillance as a treatment strategy in low-risk (urological) cancers

The global burden of low-risk cancers is expected to continue to increase due to an aging population, better screening practices and diagnostic tools and a subsequent increase in incidence. This is clearly demonstrated in prostate cancer, which now accounts for 400,000 new cancer prostate cancer cases across Europe (1), 160,000 in the US (2) annually, and is now the second most frequent malignancy (after lung cancer) diagnosed globally—1,276,106 men (3). This has largely been driven by an increasing use of prostate specific antigen (PSA) testing and more refined diagnostic imaging and biopsy procedures. This in turn has led to a significant worldwide shift in staging whereby 10–80% of men are diagnosed with localised, low-risk prostate cancers (4-6).

Current European guidelines suggest that in a large proportion of men diagnosed with low-risk prostate cancer immediate radical treatment is not required. These men can be safely monitored using a series of tests including; PSA, rectal examination, prostate biopsy and/or magnetic resonance imaging (MRI)—an approach labelled active surveillance (6). However, despite the potential to actively monitor low-risk prostate cancer with little risk of disease progression (<0.03% over 15 years) (7), the reported uptake of surveillance varies significantly across countries, regions and individual hospital sites (8). And even where the uptake of surveillance is higher, the drop-out rate within the first 2 years of diagnosis is reported to be as high as 38%—despite no evidence of disease progression (7).

Low acceptability of long-term surveillance strategies results in overtreatment, unnecessary adverse events, and a higher health economic burden. Similarly, this phenomenon has been observed in other tumour groups, including low-risk kidney cancer (9).

There are several management options for localised (stage I and II) small kidney masses (10). In addition to radical or partial nephrectomy and percutaneous ablation, there is also the option of active surveillance—which has been shown to have safe oncological outcomes (11,12). This option is currently underutilised and there is demonstrable overtreatment in this patient group (13). A greater appreciation of the potential harms of overtreatment as well as the barriers and facilitators to active surveillance selection is therefore crucial to optimise the number of patients undergoing active surveillance protocols (13).

The need for acceptability of long-term surveillance

Given the projected increasing burden of low-risk cancer, there is an imperative to develop a research methodology aimed at improving the acceptability of long-term surveillance for a variety of low-risk cancers. This methodology needs to address the complexity of the issues cancer patients face that are directly associated with choice and acceptability of surveillance combined with an approach aimed at exploring the depth of healthcare professionals understanding of these concepts. The understanding and prioritisation of both the barriers and facilitators to

surveillance would then provide means for research themes to study interventions aimed at increasing both the uptake of and adherence to surveillance.

Thus, to address the increasing problem of low acceptability of surveillance in low-risk cancer patients, there is a need for methodological innovation bringing together existing theoretical approaches and methods in an interdisciplinary setting.

Methodological innovation—a first exemplar in prostate cancer

In the context of prostate cancer, we have undertaken an initial attempt to address this methodological need. As described previously, despite support in international prostate cancer guidelines for active surveillance as a treatment choice for men (EAU, AUA), this strategy is erratically applied, suggesting underutilisation across the board. In addition, when chosen the surveillance drop-out rate over a short timeframe is high (7).

We employed a four-stage modified Delphi technique to achieve consensus on supportive care measures for active surveillance (14).

- Stage 1: Data collection: 5-year review of an active surveillance intervention aimed at improving long-term active surveillance adherence (15), contemporary review of active surveillance cohorts worldwide (16), and a systematic review of the barriers and facilitators to active surveillance choice and adherence (17).
- Stage 2: Qualitative study: semi-structured interviews were conducted with men who had opted out of active surveillance without evidence of disease progression.
- Stage 3: Data synthesis and Delphi survey: A meta aggregation of qualitative and quantitative data from stages 1 and 2 to inform a two round patient and public engagement Delphi survey.
- Stage 4: Consensus: Expert Active Surveillance Reference Group (ASRG) consensus statements.

The findings from Stage 2 are published in this special issue (Beckmann *et al*.).

In summary, the following six key themes were identified and found to influence both choice and adherence to active surveillance: (I) cancer characteristics (tumour volume and grade, PSA level); (II) patient factors (age, ethnicity, co-morbidity, education level, socio-economic status, family history of cancers, fear of progression and/or side-effects of treatment); (III) family and social support (access to support groups, education of family, spousal encouragement); (IV) provider (communication style, attitude of healthcare professionals); (V) healthcare organisation (administration of cancer pathway, support, type of surveillance strategy) and (VI) healthcare policy (guidelines, patient selection, consistent clinical guidance). These were further interwoven with experiential factors associated with diagnosis, medical consultations and the shared decision-making process, the type and variety of information and supportive care offered, administration of the surveillance pathway and the influence of family and peer support in the context of both choice and adherence to active surveillance.

Patients and healthcare professionals had noticeably different priorities for active surveillance supportive care; however, following a review of these in Stage 4, the ASRG were able to agree on 24 consensus statements of best practice in supportive care that encompassed: (I) applied principles of an active surveillance programme; (II) structure of medical consultations; (III) content of information and support packages; (IV) method of information delivery.

From this first methodological innovation project, it can be concluded that many factors influence a men's choice and adherence to active surveillance, and it is common to find that when asked health care professionals prioritise very different aspects of supportive care to those highlighted by patients. It is therefore essential to learn from this by implementing a robust patient and public engagement process that covers the process of both evidence acquisition as well as the design phase of any future interventions aimed at increasing active surveillance choice and adherence in low-risk (urological) cancers.

Methodological innovation—the future

Where answers lie in the outcomes, perceptions, views and experiences of both patients and healthcare professionals a mixed methods public engagement approach is optimal. We propose that further development of the above outlined research methodology is based on tweaking, layering and adapting this existing mixed method approach. We would like to encourage clinical researchers to further fine-tune our method through a process of testing and evaluation in other cancers, so that it can be applied to the many chronic disease settings where a long-term active surveillance strategy is the appropriate management plan.

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