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EDITORIAL COMMENT

How to improve cancer care by use of guidelines and quality registers

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The ultimate aim of guidelines and quality registers in cancer care is to ensure that each cancer patient receives optimal treatment in a timely fashion. In order to do so guidelines provide evidence-based recommendations, and assessment of adherence to the recommendations can then be made by use of data in quality registers. In addition, these registers provide an excellent basis for auditions of pattern of care and for post authorisation safety studies (PASS) of rare adverse effects of medical treatment.

In Sweden, a large number of national guidelines have been published, and there are many quality registers in operation. The aim of this editorial is display the usefulness of guidelines and quality registers, and the potential synergy between them by highlighting some recent publications in The Scandinavian Journal of Urology.

Guidelines

In guideline working groups, large efforts are devoted to searching the literature for evidence, grading evidence, and formulating recommendations for best cancer care.

Scand J Urol has recently published some articles summarising updates of national guidelines on prostate cancer and bladder cancer [1–3]. These articles highlighted newly added guideline recommendations and some minor differences between the Swedish guidelines and the European Association of Urology (EAU) guidelines.

Despite the large efforts in the production and dissemination of guidelines, and the considerable attention they receive, surprisingly little is known about adherence to them in clinical practice and the consequences of low adherence. However, in Sweden, data in quality registers can be used to measure adherence to guideline recommendations.

Ideally, open and timely reporting of these measures can then provide an incentive to improve adherence at each point of care.

Quality registers in uro-oncology

In the field of uro-oncology, there are four quality registers in Sweden, also known as clinical cancer registers. These are registers for prostate cancer, bladder and urothelial cancer, renal cell cancer, and penile cancer. In almost all publications based on quality registers in Sweden, the study database is enriched with data from other nationwide, population-based health care registers such as The Cause of Death Register, The Patient Register, and The Prescribed Drug Register in order to add data on pertinent variables that are not registered in the quality register.

Standardised care pathway for suspected bladder cancer

A standardised care pathway for patients with suspected bladder cancer was introduced in 2016 in Sweden with the aim to decrease waiting time from first symptom to definitive treatment [4]. Data in The Swedish National Register of Urinary Bladder (SNRUBC) on waiting times for more than 26,000 patients before (2011–2015) and after (2016–2019) the pathway introduction were compared. There was an improvement in waiting times, although quite modest, median time from date of diagnosis to date of transurethral resection of the cancer decreased from 37 to 27 days, and essentially no change in cancer characteristics at the time of diagnosis was observed.

Prostate cancer diagnosis at cystoprostatectomy

In men who undergo radical cystoprostatectomy for bladder cancer one out of three men are diagnosed with prostate cancer at histopathological examination of the specimen. This is similar to the proportion of men who are detected with latent prostate cancer at autopsy who died of other causes than prostate cancer. For many men follow-up after cystoprostatectomy include Prostate-specific antigen (PSA) testing. The need of such testing was investigated in a recent study in The National Prostate

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Cancer Register (NPCR) of Sweden [5]. At 15 years of follow-up of 1,500 men diagnosed with prostate cancer at cystoprostatectomy performed for bladder cancer, the cumulative incidence of prostate cancer death was 2.6% according to the Cause of Death Register. However, a substantial part of these men whose death was attributed to prostate cancer likely did not die of prostate cancer since they had not received androgen deprivation therapy before death, which a large majority of men do as reported from NPCR previously. There seems to be little need for PSA testing in a vast majority of men who have had their prostate removed during a cystoprostatectomy performed for bladder cancer.

Complications after nephrectomy

All 5,505 patients in The National Swedish Kidney Cancer Register who underwent surgery or thermal ablation for kidney cancer in 2015–2019 were identified [6]. Nine percent of these patients had a major (Clavier-Dindo III-V) complication, the most common complications were bleeding and infection. 90-day readmission rate was 6.0% and 90-day mortality was 1.5%. Low preoperative comorbidity, small tumour size, good kidney function, and good surgical technique were all associated with low risk of complications.

Urinary incontinence after prostatectomy

The association between surgeon volume and urinary incontinence after radical prostatectomy was assessed by use of a PROM questionnaire 1 year after robot-assisted radical prostatectomy in 4,668 men in NPCR [7]. 14% of men were incontinent after surgery. Surprisingly, there was no statistically significant association between surgeon volume and incontinence; there were large differences in the proportion of incontinent men also between surgeons with similar annual volumes as recorded in NPCR. These data underline the importance of feed-back to the surgeon on functional outcomes after prostatectomy.

Doublet therapy for metastatic prostate cancer

Upfront doublet therapy, i.e androgen deprivation therapy plus an androgen receptor pathway inhibitor (ARPI) or chemotherapywith docetaxel, has been shown to increase survival in men with newly diagnosed, de novo metastatic prostate cancer in a clinically meaningful way. Reimbursement for abiraterone for the indication *de novo* metastatic prostate cancer was approved by the Swedish health technology assessment agency in June 2018 and abiraterone was subsequently recommended by national guidelines for this indication. By use of data in NPCR and the Prescribe Drug Register use of doublet therapy was investigated in men diagnosed January 2018 to March 2022 [8]. Slightly more than half of men with *de novo* metastatic prostate cancer and a life expectancy more than 3 years received doublet therapy. There was a two-fold increase in use of this treatment during the study period, and there were large differences in the uptake of doublet therapy between regions. Increased adherence to guidelines seems warranted.

Time to castration-resistant prostate cancer

In a study of 1,603 men in NPCR who received GnRH agonist treatment, the risk of transition to castration-resistant prostate cancer (CRPC) was investigated by use of data on PSA in the Uppsala-Örebro PSA Cohort and Stockholm PSA and Biopsy Register [9]. Half of the men transitioned to CRPC and risk of CRPC was strongly related to high Gleason score and high PSA after start of GnRH, whereas PSA measured before start of GnRH was not associated with risk of CRPC.

Debunking the myth that ADT protects against COVID-19

Early in the COVID-19 pandemic it was suggested that androgen deprivation therapy (ADT) was protective against COVID-19 [10]. However, in a case control study of men in NPCR who died of COVID-19, men on ADT had a higher risk of death from COVID-19, likely due to that they were old, had high comorbidity, and advanced prostate cancer. No support for the hypothesis that ADT protects against COVID-19 was found in this or other similar studies.

Conclusion

The studies highlighted in this editorial show the usefulness of quality registers, aka clinical cancer registers, that are available in Sweden. These registers are powerful tools for assessing adherence to guidelines and to audit pattern of care with comparisons over time and between regions. In addition, they provide an excellent basis for population-based studies on a wide range of topics, and they are an unsurpassed basis for PASS of rare adverse effects of medical treatment, as well as putative unknown beneficial effects, as exemplified above [10].

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