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Improving QOL for cancer patients
Implementing patient-reported outcome measures (PROMs) in clinical practice

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The Netherlands Cancer Institute (NKI) is a comprehensive cancer centre in Amsterdam. Patient-reported outcome measures (PROMs), or standardised questionnaires about health-related quality of life (HRQOL), were implemented in 2021 at the NKI for use in the outpatient clinics. We aim for healthcare providers (HCPs) to discuss patients’ completed PROMs with them during outpatient consultations to better align care and supportive care with patients’ needs.

We invite patients at set times before, during, and after treatment to complete PROMs. Patients are invited by their HCP through the electronic health record (EHR); future questionnaires are triggered automatically after initial invitation. Patients complete PROMs through the EHR’s patient portal. Currently, cancer patients from 10 various types of cancer are invited to complete PROMs. About 70% of patients complete baseline PROMs, and 56-70% complete follow-up measurements.

Electronic health records
Patient’s PROMs are automatically saved in the EHR and the outcomes are presented on a dashboard. We can see the outcomes of several PROMs over time in a graph, enabling us to inspect trends in scores. We have applied thresholds of clinical importance [1] to facilitate interpretation of the scores: scores that are worse than the thresholds are reported in red, scores that are better are reported in green. This facilitates a quick overview of scores that require clinical attention.

Personalising care
Upon discussing PROMs, HCPs can refer patients to clinical and non-clinical supportive care services. However, if they are unsure which referral to make, they can ask for triage by a specialised supportive care nurse at the NKI ‘Centre for Quality of Life’ [2]. In one or several consultations, these nurses can unravel patients’ supportive care needs and propose fitting comprehensive care recommendations. We are currently also implementing self-support tools and recommendations in the PROMs dashboard, including patient information, self-help apps, eHealth tools, and decision-support tools that the patient can access upon discussing their PROMs with the HCP.

Experience from NKI
In the Urology Department, PROMs have played a fundamental role for 10 years already, particularly in the field of prostate cancer (PCa). PROMs are taken into account in shared decision making (SDM) and in routine clinical follow-up to monitor the side effects of treatments from a patient’s perspective. The PROMs patients complete questionnaires are validated: EORTC QLQ-C30, EORTC PR-25, IPSS, ICIQ-SF, and IIEF. PROMs are completed online. In case of non-response, a paper version is sent to patients. The response rate is high: 90% before any treatment, and 77%, 86% and 82% at 6, 12 and 24 months after prostatectomy, respectively. [3]

Shared decision-making
Several treatment options are available at the NKI for men diagnosed with primary localised PCa, including radical prostatectomy (RP), external beam radiotherapy, brachytherapy, and active surveillance. Many men with localised PCa are referred to our institute for treatment. PCa patients complete PROMs before their first consultation. Some patients have a preference for brachytherapy or for neurosafe prostatectomy. Following a patient’s PROMs, we can explain that brachytherapy is not an option due to lower urinary tract symptoms, as shown in the example above (IPSS of 20). The QLQ-C30 questionnaire also gives an indication of the patient’s physical and mental condition. Of course, the final treatment decision is not based solely on the PROMs. Clinician reported outcomes (CROs) and patient preferences are also taken into account. In the example above, a patient may have an IIEF-EF score of 1/30, which does not necessarily mean that he has low erectile functioning. On further questioning the patient, it may be that the patient has not been sexually active in the last month, but has a normal erection. This patient could then opt for a neurosafe prostatectomy.

PROMs after RP
The most bothersome side effects of radical prostatectomy (RP) are urinary incontinence and erectile dysfunction. The NCI sends PROMs out at 6, 12, 24 and 36 months after RP. We recently demonstrated the impact of discrepancy between PROMs and CROs after RP. [4] Urinary

Fig. 1 Example of results of the PROMs as they appear in the NCI database

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Practice experience
Ms. Tiller: “I have to admit that I use the PROMs during the follow-up after RP for more than 10 years. I have 10 minutes for each consultation and it does not take more time to address the PROMs in the conversation with patients. I always discuss the abnormal scores of the PROMs with patients; however, I also check whether the "good" scores match the patient’s physical and mental condition. From my experience, I have noticed that patients are satisfied that PROMs are discussed in the consultation.”

References

My name is Ms. Lisbeth Leinum (DK), I am 45 years old, and work at Zealand University Hospital, Roskilde (DK) in the Dept. of Urology. After graduating from high school, I worked for six months in a hospice in Jerusalem and was motivated to study nursing. In 2004, I received a BSc in Nursing, and began my nursing career in an elective surgical ward in Copenhagen, followed by an acute surgical ward. Since 2011, I have been working in urology.

My motivation as a member of the EAUN Board is to raise awareness to the crucial role of specialised urological nurses in providing quality care in wards and outpatient clinics. By collaborating internationally, we can share knowledge, practices, and inspire each other, thereby strengthening urological nursing and enhancing patient care. Last year, I joined the Bladder Cancer Special Interest Group, and I am also a member of a national steering committee developing an educational programme for nursing staff regarding intravesical instillations.

Research interest
I am enthusiastic about nursing research, and implementing research to benefit patients plays a vital role to ensure evidence-based care. Developing and updating guidelines within the EAUN is of utmost importance to support the adoption of new evidence and I would like to contribute to this.

I have experience with both quantitative and qualitative research methods, as well as systematic reviews. My primary goal is to contribute research applicable to daily clinical practice, providing nurses with a solid knowledge base for nursing. As a member of the EAUN Board, I want to promote extensive research collaborations across urological departments, inspire and support urological nurses in reflecting on their care, undertaking practice development projects, and disseminating their experiences and insights with international colleagues.

“Developing and updating guidelines within the EAUN is of utmost importance to support the adoption of new evidence and I would like to contribute to this.”

Pre- and postgraduate training
From 2014 to 2017, I held the position of clinical teacher, which involved bedside and formal teaching, reflective sessions, simulation-based training, examinations, and administrative tasks. I completed the Diploma of Health in Clinical Training and Health Education with a project focusing on study wards, preparing nursing students for their future responsibilities. We successfully implemented a study ward and published a paper on our experiences.

Currently, alongside my PhD studies, I develop urological nursing competencies in postgraduate

European Association of Urology Nurses

A new board member for EAUN
Introducing Ms. Lisbeth Roesen Leinum

Ms. Lisbeth Roesen Leinum
PhD student, Clinical Nurse Specialist
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My name is Claire Davies, and I am a urology clinical nurse specialist working in Hereford, which is in Herefordshire, England, near the Welsh Border. I am delighted to be joining the board of the EAUN and believe passionately in 'nurses supporting nurses' across our speciality.

I graduated from Worcester University with a BSc in adult nursing in 2015, and studied at various institutions across the United Kingdom in the postgraduate setting. My major study focus recently has been an MSc in prostate cancer care at Sheffield Hallam University (due for completion in early 2024).

I have worked in urology since January 2017, starting my career as an onco-urology staff nurse. My original role was supporting patients diagnosed with a urological cancer. It was this first experience of urology that gave me the drive to learn and progress. I was appointed to my first clinical nurse specialist post in 2018, with a promotion in 2019. I currently hold the position of lead urology nurse for the service.

My role is predominantly clinical, and I undertake a variety of urology clinics and independently perform nurse-led investigations and procedures. I am a qualified prescriber, which is beneficial when supporting our patients throughout their pathways. I set up a nurse-led local anaesthetic transperineal template prostate biopsy list and am proud that this is a service we are able to offer our patients. We currently run a nurse-led male LUTS assessment clinic in line with our current National Policy in the UK. This has been successful and helped reduce our waiting times and access to service. It has been extremely well received by patients. I was delighted to be able to share our progress and learning points at the annual BAUN conference. I am an active member of the local expert advisory group for urological cancer. I have been fortunate to participate in conferences both nationally and internationally and I am always keen to share learnings where I can.

"Access to support can take many forms and this is why I joined the EAUN."

One of the other important aspects of my role is team development. I feel it is a privilege to support and mentor new members of the team through their training to become independent urology clinical nurse specialists, from formal mentorship via university courses, to ad hoc support and supervision as identified.

I hope via my participation with the EAUN board, to be an advocate for both nurses and patients working in and using urology services. One of the biggest challenges faced by nurses in the UK is access to education training and support. Access to support can take many forms and this is why I joined the EAUN. Learning for personal development and sharing best practice are valuable opportunities that need to be available to everyone.
Dear EAUN members,

The growing evidence in urology nursing care is amazing!

With this column, the EAUN Special Interest Groups want to put the spotlight on recent publications in their field of interest. This month’s articles have been carefully chosen because of the scientific value from PubMed and other sources and represent different methods and approaches in research and development in urological nursing care.

We hope this initiative will have your attention and continuously provide information on “spot-on” urological nursing care. If you would like to inform us and your colleagues about new initiatives or exiting developments in one of the special interest fields you can contact us using the email addresses below.

Best regards

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Selected from PubMed and other sources

Bladder cancer

This article is the first to provide the bladder cancer community with long-term results on the efficacy of prehabilitation in MiBC pathways. This is a major breakthrough for continuously optimizing the care pathway and patient outcome:


The two following well-performed reviews articles are recommended to bladder cancer nurses with current practice who would like to be updated:


The first study within bladder cancer using a ‘trials within cohorts’ study design:


Continence


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New research and developments

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Approved for publication by the EAUN Executive Committee.

January/February 2024
Prostate Cancer

Sexual Health
• Raaij J van, Janssen PKC. The rs296 polymorphism in the 5-HT1b receptor in Dutch men with lifelong premature ejaculation: a genetic case-control association study. JSM. 2023; qdad159. Doi: 10.1093/jsxmed/qdad159. https://doi.org/10.1093/jsxmed/qdad159
• Osadchiy V, Elsawarapu SV. Endocrine disruptors and male sexual health. JSM. 2024;21(1)1–3. doi:10.1038/s41585-023-00840-0

State-of-the-art nursing programme
The nursing programme has been developed following feedback from our previous successful programme in 2023. It will also build upon previous experience and gained knowledge from our peers. We will offer theoretical in-depth knowledge on various common robotic procedures, but also elaborate on the expanding role of the nurse, the development of best practice competencies, and working in a robotic team.

• For experienced and inexperienced OR nurses and RNFAs, and for those with an interest in working in a robotic urology multidisciplinary team
• 3-day or 1-day registration, early fee until 15 June
• Registration for the optional hands-on training course is on first-come, first-served basis
• In conjunction with the 21st Meeting of the EAU Robotic Urology Section

An application will be made within the EU-ACME/CNE programme for CNE accreditation of this event.

European Association of Urology

ERUS-EAUN24
21st Meeting of the EAU Robotic Urology Section
11-13 September 2024, Bordeaux, France
www.erus24.org

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Ms. Casey: “The meeting presents the latest in science and education in various formats to suit the needs of all participants (such as urology nurses, continence nurses, stoma care nurses, oncology nurses, operating room nurses, etc). These learning methods include plenary and special sessions, state-of-the-art lectures, panel discussions, poster sessions, thematic sessions, two ESU courses, and hands-on training.

Day 1 (Saturday, 6 April)
The prostate cancer special interest group will conduct a thematic session on ‘Improving sexual health before and after prostate cancer treatment’. This will include thought-provoking sessions on subjects such as non-surgical predictive factors for erectile dysfunction after prostatectomy, the role of prehabilitation, supporting gay and bisexual men with prostate cancer and supporting older men with prostate cancer.

“In the afternoon, we will also have a debate on prostate cancer screening; ‘Prostate cancer screening provides little benefit and can be harmful versus prostate cancer screening is necessary’. This session will conclude with the voice of a patient with prostate cancer.”

Day 2 (Sunday, 7 April)
The day begins with Plenary Session 2 on the impact of cystectomy on quality of life and how to improve this. “This session will provide delegates with a better understanding of the importance of ongoing care for cystectomy patients to promote self-management for a better quality of life.”

“The endourology special interest group will chair a thematic session on ‘Advances within endourology and robotics. There will be a state-of-the-art lecture on ‘Managing worry and fear of recurrence’, which will provide an understanding of current models of worry, FCR and trauma-informed care, discuss specific steps required for effective nurse-led input and enable identification of where referral for additional specialist input is indicated.”

Day 3 (Monday, 8 April)
“A session has been dedicated to disseminating the changes and additional topics in the updated EAUN intermittent catheterisation guidelines. Also, before we close with the annual awards session, we will discuss the important topic of urology nurses’ wellbeing and resilience”.

This is just a tiny glimpse of our exciting three-day scientific programme. To access the full programme, please visit the website.
Prostate carcinoma (PCa) accounts for 25.4% of all the types of cancer diagnosed in males in Germany. 60,000 males in their mid-60’s are diagnosed with PCa every year. The overall age is approximately 69 years. By 2050, the male population over the age of 60 is estimated to rise to approximately 28 million (37% of the total population), which is expected to result in the same proportion of increase of PCa patients.

Although many experts consider this form of therapy to be the best, there are risks involved, which can lead to various post-operative restrictions.

Despite being free of the tumour, post-operative quality of life (QoL) plays an important role in rating the therapy success. Changes often experienced by patients include bladder incontinence and erectile dysfunction, as well as general health problems such as fatigue and sleep disorders. They often notice an increase in emotional burdens before the therapy begins. It is important to discuss these problems early with the patients and to advise them of possible solutions. Adequate advice regarding fears and side effects of the therapy is the groundwork for the full treatment concept (Holze et al. 2012). Urotherapists can contribute to a positive outcome with counselling, education and guidance during the pre-operative phase, as well as during the treatment process.

**Urotherapeutic guidelines**

It was our goal to develop the first guideline not only for the urotherapists involved in the therapy of locally situated PCa, but also for others involved in the therapy for patients and their carers or relatives. In addition, the guidelines serve to make the work of the urotherapists transparent and reviewable within the multi-disciplinary team. For this reason not only urotherapists with nursing expertise but also physiotherapists, nursing scientists, urologists and patients have contributed valuable input to these guidelines.

**Therapy and QoL**

Regarding the post-operative limitations, despite the operating methods to reduce damage to nerves, urotherapeutic treatments become more meaningful for all those connected to the recovery process because of the increase in cases. With advice, education and training already in the pre-operative phase and during the whole period of the treatment, urotherapists can make an important contribution to the treatment process by fostering coping strategies and supporting affected males to improve QoL.

The guideline is based on the means of treatment and collaborates the results of medically indicated therapy carried out as well as questions on subjects such as food, skin care and assistance. The aim is that patients receive assistance in urotherapy in all phases of overcoming the illness.

Urotherapeutic education uses aspects of cognitive behaviour therapy and fundamentals in theoretics teaching in order to support people to adapting to their condition.

Various prostate centres in Germany offer urotherapeutic guidance to patients. The guideline offers assistance to the medical personnel involved, including urotherapists. Professionals’ pre-operative counselling and education are given to the patients before the pain from the operation causes limitations. This includes specific exercises in awareness of pelvic floor, perception and training contraction muscle control in order to actively help the recovery process.

Individual needs change the course of treatment “Specific situation/right time” is key for the treatment guideline (Wenneberg et al 2001; National Institute for Health and Care Excellence (Nice) 2021).

During the pre-operative phase, the cancer illness and unwanted side effects of the operation are foremost. Most often it is best that patients attend extended patient-education in a clinic for approximately two weeks before the operation for educational instruction. In this time, anatomy and psychology of the excretory and sexual organs, as well as pelvic floor, are discussed with patients. Knowledge regarding the ability to regulate areas in the lower body or to rest are shared. The training should deal with pelvic floor activity such as retracting and relaxing, continence training, breathing exercises, post-operative instructions in standing, and lower leg exercises to prevent thrombosis risks.

This is the time to offer psychological guidance and sexual therapeutic advice. Post-operative information regarding suppression of excretory, as
well as further examinations are required. Patients are dealing with a new life changing situation with the awareness of a new masculinity (Kong et al. 2017). In this post-operative time the individual needs of patients should be discussed, such as: current and future behaviour goals; and further advice and guidance in catheter care, skin care, and assistance. Advice on drinking, eating, toilet visits (including the positioning of the toilet), as well as pelvic floor/ micturition training, are also discussed. Relaxing methods and also sport activities are part of this individual advice.

Patients experience physical, sexual, and social changes, as a result of the operation and the cancer disease. This must be dealt with in the rehabilitation period. Information in follow-up treatment can be integrated according to the needs of the patient. During all patient contact the urotherapist has questions about the actual wellbeing. If necessary, contact with other members of the multi-disciplinary team can be arranged (e.g. urologist, physiotherapist, psychological oncologist, social worker).

Quality of life and patient education
Every patient has the right to comprehensive rehabilitation, and voluntary participation in urotherapeutic guidance is recommended for the wellbeing of a PCa patient. Urotherapeutic education is essential in order to enable patients to deal with daily side effects experienced with PCa. Additionally, addressing psychological and social challenges, as well as a successful return to work (Heuveling 2021), are essential components of the patient’s holistic care.

As a result of a cancer diagnosis and dealing with coping strategies some patients forget the information received during the initial treatment time. For this reason, now is the right time to repeat information and discuss individual problems within a multi-disciplinary team or to make appropriate support available to those affected.

Conclusion
The guideline is a unique treatment suggestion for all involved in the education for patients before and after a radical prostatectomy with non-invasive PCa. It describes the urotherapeutic options for patients, their carers and relatives in all phases of treatment with the assistance of a urotherapist, and a multi-disciplinary team.

References
8. Lorch/Alberts, 2015; Leitlinienprogramm Onkologie (Deutsche Krebsgesellschaft, Deutsche Krebshilfe, AWMF, 2021; Krebsinformationsdienst (KID) / Deutsches Krebsforschungszentrum (DKFZ) 2020 & 2021