Experiences of group support for mPCa patients

Specialist nursing role in advanced PCa is multi-faceted and requires careful planning

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Men with metastatic (advanced) prostate cancer have a variety of supportive care needs including physical issues, communication, physiological/emotional needs, intimacy and sex, and information (Patterson et al 2017).

In addition, we know from the work presented by Afshar et al at the EAUN Meeting in Copenhagen in 2017 that patients with a urological malignancy are five times more likely to commit suicide than those in the general population and that the ratio of suicide attempts to completed suicides was lower in patients with prostate cancer than that in the general population (1:7 vs. 1:25).

The specialist nursing role in advanced prostate cancer is varied, but may include:

- Support at diagnosis and regarding treatment decisions;
- Improving adherence and managing non-adherence to treatment;
- Monitoring treatments, response or progression and referral as appropriate;
- Proactive management of side effects and metabolic effects;
- Crisis management and rescue work;
- Support groups and education events;
- Finance and practical advice; and
- Advanced care planning and palliative care

Provision of supportive care can take place in a variety of ways, depending on patient preference and service demands. These may include face to face in consultations, nurse-led clinics, via assessment tools, by phone or email, through groups or seminars or other support-based activities

The use of seminars and support-based activities can be an efficient and cost-effective way of reaching men. At Guys and St Thomas NHS Trust in London (UK) we have had a successful support group for many years and have also been using seminar-based events ("Healthy on Hormones") to provide specific support and information for men on androgen deprivation therapy. We have also recently obtained charity funding for an associated project called the "Advanced prostate Cancer Club".

"Providing forums where men can get information and support has been successful and rewarding for staff as well as patients."

Support group

Our support group (Prostate life!) has been running for over 10 years at Guys Hospital and is open to any man who has been treated for prostate cancer at our hospital (regardless of treatment or stage). The sessions are popular and numbers of attendees have increased year on year. The group also has an email distribution list where members are kept up to date with information about meetings, news and information

The meetings have a standard format: we start with an educational topic followed by the support element where members are able to talk amongst themselves or ask for specific advice. Refreshments are provided which adds to the relaxed and friendly environment. Some of the attendees have sent in their comments about what the support group has meant to them. Below are some testimonials:

"I have found the Support group extremely useful... The ability for new patients to be able to talk with men who have undergone treatments and explain how they have been affected and how they feel afterwards, is invaluable and offers reassurance."

"Since coming to the support group over the past seven years the group has been very supportive towards each other. Through shared experiences the group has helped me overcome the fear, anxiety and anger that having cancer gives you. The lectures have helped us understand our condition at the various stages we are at."

"The support group has made up for a major gap in my experience as, until diagnosed, I had no friends or relations with the disease and no prior knowledge of it. The group meetings have provided a very friendly and supportive framework and I am very grateful for the help and encouragement given by other members and all the professionals involved."

Staying Healthy on Hormones Seminars

We know that there is a need for support and education for men on ADT around side effect management and metabolic effects. However, most education and support is given 1:1 in consultations or over the phone, often in the context of a nurse-led clinic also dealing with treatment response or disease progression. Information given in this way is not always retained and referrals were often not taken up when advice regarding side effects and heathy living were given in the context.

The aims of the seminar were to understand treatment and its side effects, and offer advice regarding side effect management, to suggest simple lifestyle changes to mitigate longer term metabolic effects, and, finally, to empower men to engage with primary care and take an active part in their monitoring and care (improve self-efficacy)

A total of 306 men and 74 friends/partners have attended the seminars and 289 evaluations have been completed. The evaluations have been extremely positive with most men finding the sessions useful, and all men saying that they would recommend the seminars to other men on hormone therapy

Advanced prostate cancer club

We received a legacy donation from one of our patients for support for men with advanced prostate cancer. The donation was specifically for "palliative care". We have set up a project to use the donation to provide Healthy on Hormones seminars, but also run a selection of small groups and workshops specifically for men with advanced prostate cancer based on palliative care principles. Palliative care aims to treat or manage pain and other physical symptoms. It also aims to help with any psychological, social or spiritual needs. The goal is to help patients and everyone affected by a diagnosis to achieve the best quality of life.

To inform the project, we ran a focus group for men and partners and also canvassed ideas from staff working with men with advanced prostate cancer. We asked what would be useful, whether there were unmet information needs, ideas for activities and groups, and where and when it should take place.

The themes discussed by the groups included, emotional support, understanding what support was available, help and advice with getting affairs in order including advanced care planning, financial help, physical issues including managing pain and fatigue, and activities where men could meet other men such as art and photography, day trips and gym and social events

The first events organised are two-day trips and a course on art classes in order to build a community of men. We are working with palliative care to set up some more challenging events to discuss issues around death and dying, but the initial groups are around building a safe and supportive community where, through activities such as art and exercise, we can start to gain trust, peer support and open up some important lines of communication.

Providing forums where men can get information and support has been successful and rewarding for staff as well as patients. The advanced prostate cancer club builds on our experience with support groups and seminars and will be a valuable addition to the support we can offer to men, as we use non-medical locations and activities to provide a safe space to get support and discuss challenging issues.

Reference

Patterson et al 2017 Unmet Supportive Care Needs of Men with Locally Advanced and Metastatic Prostate Cancer on Hormonal Treatment: A Mixed Methods Study. Cancer nursing 40(6)

Nurse-led flexible cystoscopies

Reducing anxiety in patients, building trust in disease management

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As a nurse cystoscopist, some of the most vital aspects in care management of surveillance patients with non-muscle invasive bladder cancer (NMIBC) include continuity of care, timely follow-up, and having a specific point of contact. These allow patients to have trust and confidence in the management of their disease.

I carry out a weekly flexible cystoscopy list solely for NMIBC patients who require surveillance post treatment and have undergone transurethral resection of bladder tumour, intravesical Bacillus Calmette-Guérin (BCG), chemotherapy and radiotherapy follow-up. This group of bladder cancer patients requiring surveillance are unique; they adhere to strict follow-up guidelines and need regular surveillance flexible cystoscopies, which can lead to lifelong care.

Hospital attendances can involve the fear of the cancer recurring, anxiety and worry about pain. Having spoken to regular surveillance patients, I am aware that they find comfort in knowing they see the same person every time they go to the clinic for their flexible cystoscopy. The doctors' posts continually change and their clinical demands are high. Having a nurse cystoscopist, whom the patients already know perform the "dreaded check cystoscopy", can reduce their anxiety.

There are no studies specifically dedicated to determining patient anxieties regarding nurse-led flexible cystoscopy. Data from a personal cohort initially demonstrated that 97% of patients said that they were happy with a nurse specialist to perform the cystoscopy again in the future. The 97% became 100% as the patient who was unsure at first changed his mind, and confirmed that if the same nurse performed the procedure, he would be more than happy.

As a specialist bladder cancer nurse, I feel fortunate to meet the patients at the beginning of their bladder cancer journey – from initial diagnosis, administration of intravesical treatments, to surveillance flexible cystoscopy (if that is the follow-up route taken).

Questions have been raised about the cost-effectiveness of nurse-led flexible cystoscopy. Historically, it has been documented that a nurse may not see as many patients as a doctor would, but this number will increase as the nurses gain more experience. It has also been recognised that nurses can be trained to carry out cystoscopy and identify abnormalities as accurately as urologists could. It could be argued that the nurse provides a more holistic approach by allowing more time for their consultation.

During my cystoscopy consultations, I always ensure that the patient understands the procedure and feels relaxed. When needed, I distract them by engaging in different topics of conversation unrelated to the procedure. I recommend to let patients watch a cystoscopy video and give them as much or as little information as they require, based on the assessment during the preliminary meeting. When patients have sufficient preparation, psychological care, continuity, and a point of contact, I am confident that nurse-led surveillance cystoscopies can significantly reduce their anxieties.

Certainly in the United Kingdom, only senior and experienced clinical nurse specialists should be selected for flexible cystoscopy training as specified in the British Association of Urological Surgeons (BAUS) and British Association of Urological Nurses (BAUN) guidelines. It is recommended that the nurse will have had two years' experience in urology and have the support of a consultant urologist to undertake flexible cystoscopies. This is imperative for the training process to be successful.

During training, it is advised that a nurse completes a comprehensive in-house training programme led by a consultant urologist. Additionally, they should demonstrate their knowledge and competence by completing a training booklet and undergoing assessment, so both nurse and consultant urologist are satisfied that the nurse can work independently.

The Training Tool I used was adapted from the BAUN/BAUS guidelines and endorsed by the local trusts clinical governance team and the heads of nursing and urology department. The tool was divided into four sections. These were: Theoretical, Observational (minimum 10), Practical (minimum of 50 supervised as recommended by BAUN), and Consolidation of practical competence (30 unsupervised) with confirmation of the accuracy of findings overseen by the supervising urologist. These findings were retrospectively reviewed using video data to ensure consistency. A nurse cystoscopist report was devised for the nurses' portfolio to keep a log and evidence of training using video cystoscopes.

The theoretical component comprised of a Self-Directed Learning Package which includes the anatomy and the physiology of the bladder; investigations of haematuria; bladder cancer overview; principles and workings of a cystoscope; complications and antibiotic prophylaxis; follow-up protocol; and up-to-date literature for reference.

Are you interested in learning how to be a nurse flexible cystoscopist? Do you want to provide high-quality service, and consistency for your patients? Or would you like to know how to hold a scope and learn the principles of cystoscopy? Come and join us at the flexible cystoscopy workshop at the 20th International Meeting of the European Association of Urology Nurses (EAUN19) in Barcelona. Grab the opportunity to learn the basics and apply your new skills in your local hospitals.

BAUS Conference Report

Updates on haematuria, urinary tract cancer and new BCa studies

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Recently, I attended the BAUS conference held at the BT Convention Centre in Liverpool, England last June 25 to 27. I was joined by a few urological colleagues from New Zealand and Australia, but accents were predominantly British and European. There were around 950 names on the published delegates list but I was unable to ascertain the breakdown of medical staff, nursing and allied health workers.

I was very much looking forward to this, my first British conference given the similarities between the New Zealand healthcare system and the National Health Service. I was not disappointed, finding the conference sessions stimulating and relevant to our healthcare environment. I particularly enjoyed the thought provoking session hosted by BURST Research Collaborative. This is a trainee-led research group comprised primarily of urological registrars, supported by consultants, junior trainees and medical students. The aim of the collaborative is to produce high impact multi-centre audit and research that can improve patient care. They also offer on-line education series aimed at honing the research skills of health care practitioners.

At the conference, the group updated us on their project called 'MIMIC.' This is a multi-centre cohort study designed primarily to establish the relationship between White Blood Cell (WBC) on admission and spontaneous stone passage (SSP) in patients discharged from emergency department after initial conservative management. The hypothesis of the study is that a raised WBC is associated with decreased odds of SSP and it is hoped that the evidence from this study will guide clinicians on the management of patients who present with acute renal colic.

MIMIC has closed for recruitment and its primary data analysis is underway. A BURST poster was presented at the conference on the secondary aim of the MIMIC study, evaluating the role of Medically Expulsive Therapy (MET) in SSP in patients with acute ureteric colic. The protocol included all patients admitted with acute renal colic with CT-KUB confirmed obstructing ureteric stone. Statistical analysis was used to explore the effect of age, gender, stone size and position, (upper, middle or lower ureter) on whether MET use had an effect on SSP.

Data was collected from 4181 patients. 75% (3127) were discharged with conservative management. 80% of these (2516) later spontaneously passed their calculus and were included in the multivariate analysis. Results indicated that 44% (952) were prescribed MET in the form of Tamsulosin and 56% were not (1234). The rate of SSP in the two groups was 78% and 72%, respectively. Although this is a 6% difference in favour of MET use, this effect disappeared when confounders such as stone size ad position were adjusted for in the multivariate analysis. The study therefore concluded that MET has no benefit in SSP regardless of stone size or position.

IDENTIFY's interim findings

The BURST Research Collaborative also presented interim findings from IDENTIFY, a protocol that is recruiting until the end of this year. IDENTIFY is the acronym for study: Investigation and Detection of urological neoplasia in patients referred with suspected urinary tract cancer: a multicentre analysis. IDENTIFY is a study dear to my heart as the centre where I practice collects a very similar data set on individuals that are seen at our one-stop haematuria clinic, modelled on clinic protocols in the UK. I felt disappointed not to have been aware of the study earlier, especially when I noted that around six Australian sites were participating in the data collection.

To date, 7500 patients have been recruited in just six months, a testament to the power and organisation of BURSTS international trainee network. This study is designed to inform the creation of haematuria risk stratification pathways, beyond patient age and type of haematuria (visible/ non visible). These pathways can be incorporated into urology guidelines utilised to determine the need for and type of haematuria screening investigations.

The session presenters informed us that of the 73 United Kingdom Hospitals participating in the study 82% have a one-stop haematuria clinic and 52% did routine PSA screening as part of their work-up. 52% utilise renal tract ultrasound scan as their first-line imaging for visible haematuria, with 45% using CT scan. Preliminary findings (may change after final data analysis) reveal a renal cancer diagnosis rate of 1% (78) and upper tract Urothelial Carcinoma of 1% (79). Bladder cancer was diagnosed in 14.6% of patients (970) and prostate cancer in 0.8% (51). This is from referrals for both visible and non-visible haematuria and other referral symptoms, the data not yet stratified.

One interesting interim finding is that there was a 5% cancer detection rate in under 45-year-olds, a group which the NICE guidelines excluded from the recommendation to refer to secondary care for renal or bladder cancer investigations. If this statistic is confirmed it will be interesting to see if it is incorporated into an updated NICE guideline going forwards.

The BURST team outlined the 'next big idea'- an RCT of a personalised investigative pathway for haematuria vs standard of care. The hypothesis is that personalised investigation will result in no worse cancer detection rate with lower investigative burden than standard of care. This concept was greeted with much enthusiasm from BURST Twitter followers, leaving me feeling inspired by the idea of how these large, speedy recruitment multicentre studies really have the potential to inform practice in a timely manner.

Results from the IDENTIFY study were presented by the BURST Research Collaborative

The session wrapped up with a 'Dragons Den' where three finalists presented excellent research study proposals. The study designs were critiqued by the 'dragons' with questions from the audience. Twitter and in-house voting picked the winning proposal. The author said his study would challenge the "there's no harm in exploring" mentality that often leads to scrotal exploration in acute scrotal pain. The runners-up aimed to investigate the outcomes resulting from the different practices of 'ureteric stenting with delayed definitive stone treatment' versus 'immediate acute ureteroscopy' for obstructing calculi, with the third finalist's protocol designed to try and ascertain optimal stent duration post-ureteroscopy.

I found all proposals thought-provoking along with the constructive critique they received from the dragons. I left the session feeling the future of urology continues to be in good hands. In my next column I will share some other conference highlights that confirm this view. Until then, be well.

European Association of Urology Nurses

APCC 2018 Report

Excellent prostate cancer care Down Under

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Last week I participated at the Asia-Pacific Prostate Cancer Conference in Brisbane to prepare for my nursing fellowship at the Australian Prostate Centre in Melbourne. It was a great opportunity to meet my future colleagues at the centre and acquire new knowledge about prostate cancer. I also welcomed the opportunity provided by the EAUN to pay for the registration fees in return for a conference report.

I've been working as a urology ward nurse for four years, and two years ago I started a prostate cancer nurse specialist programme at the University Hospitals Leuven. In Belgium, nurse specialists are still relatively 'new,' which makes the Brisbane meeting a great opportunity to learn from experienced colleagues Down Under.

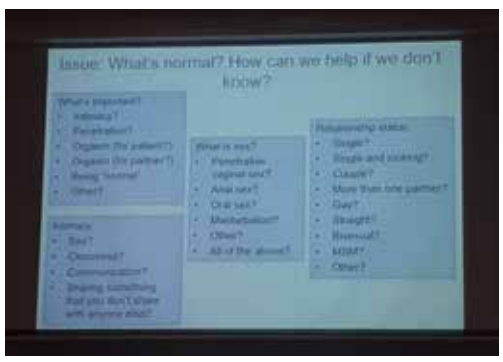
The conference itself was not as big as I expected, but it was a lot easier to network with the Australians and participants from other countries. The conference had a professional but warm atmosphere and during the breaks I got to talk to nurses, doctors, researchers and physiotherapists. I also had the chance to talk with the speakers during lunch breaks lunch to discuss some details in their lectures. One of the topics discussed was the differences in health care systems and how they affect patient care.

With a very varied programme, I attended as many sessions as possible including those that tackled nursing issues. Many of the speakers were nurses and their lectures were not only remarkable but also inspired me.

The first day took up the history and future of urology followed by the role of genetic screening and prostate cancer prevention. During the discussion on active surveillance, I realised it is a subject I could further pursue. One controversial subject discussed was lymph nodes in prostate cancer, and the lecture by Professor Walsh discussed the benefits, barriers and long-term outcomes of a lymph node dissection. He noted that there are a lot of risks when performing a lymph node dissection with little evidence that shows benefit.

"...there are a lot of risks when performing a lymph node dissection with little evidence that shows benefit."

Following the lunch break was a lecture on patients' expectations and quality of life. Although patients nowadays have access to better information they still often have unrealistic expectations, for example, regarding the efficient management of incontinence. The session made me realise that I have to provide guidance to patients without taking away their hopes. Patient education certainly involves preparing them for what might come and properly informing them of realistic outcomes.



The lectures on sexual health stressed the importance of asking the patient the right questions

Helen Crowe and Prof. Tony Costello of the Royal Melbourne Hospital (middle) with me and Christophe Orye, both from Belgium and doing a fellowship there.

Running a nurse-led clinic

The second day took up the topic of the value of a well-run nurse-led clinic. Speaker Ms. Louisa Fleure has 25 years of experience with nurse-led clinics in the UK and gave good and practical examples on various management strategies. I noted many of her tips which I can use back home in my clinical practice, putting theory into actual practice. The rest of the day included lectures on sexual health with many helpful recommendations and insights from the speakers. One of the most significant things I picked up was the importance of carefully listening to patients. Some questions to consider are: *What is the goal? What is the patient expecting? What does the partner want? Do they want the same thing? How far would they go? Do they have the right information?* I will definitely have better questions to ask a patient who has a problem with, for instance, erectile dysfunction. During a 1.5-hour workshop, the participants shared experiences, dilemmas and knowledge, and It was good to realise that we basically struggle with the same clinical issues and challenges.

The last day in the nursing and allied health programme provided lectures on post-prostatectomy incontinence, a subject which I am very familiar with. The session was not only inter-disciplinary but also covered many aspects comprehensively, with insights from doctors, nurses and physiologists.

To summarise, my experience at the APCC Conference in Brisbane was very remarkable for its high quality programme and the warm collegial atmosphere. It is one of the rare meetings where I felt very welcomed and which made networking very easy.

Lastly, I would like to thank the EAUN and the APCC for giving me the opportunity to attend this amazing conference. I intend to participate in next year's conference and stay longer for the nursing fellowship. I certainly look forward to both!

The Conference Gala Dinner took place at the stunning Queensland Art Gallery

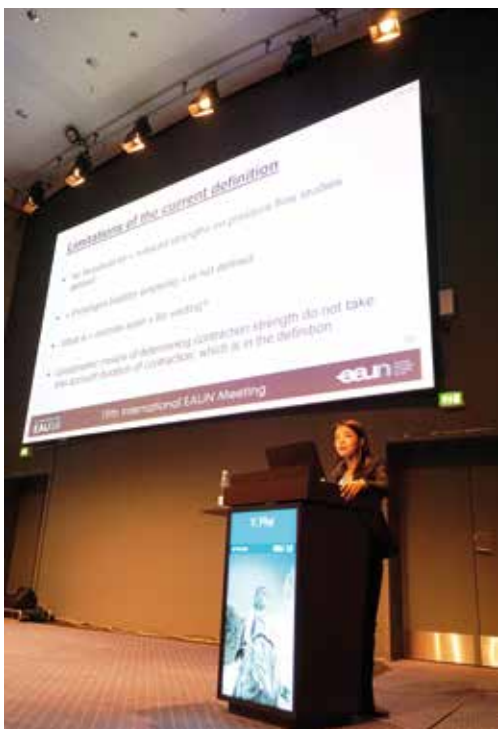
Join us in Barcelona for the 20th EAUN Congress

Share your clinical practice or research insights in the video, abstract or difficult case sessions

The EAUN extends a very warm Mediterranean invitation for you to join us in Barcelona for the 20th International EAUN Congress from 16 to 19 March 2019.

Abstract submission now open!
Deadline: 1 December 2018

Dedicated to promoting ever higher standards of urology nursing knowledge and care, EAUN19 is the largest gathering of urology nurses in Europe. The congress provides an unparalleled opportunity to examine and discuss evidence, technologies and practice across the urology care spectrum. We also offer the opportunity for participants to link up with colleagues from across the globe in one of the world's most dynamic cities.



The EAUN19's Scientific Programme is as exciting, diverse and vibrant as Barcelona itself. We will not only be looking back to recent achievements and assess how our practice has evolved until today, but will also explore the prospects that will help us meet the urology needs of tomorrow.

The EAUN Scientific Office aims to offer a programme that recognises the changing face of urology nursing. Participants can again expect a very diverse programme that will take up issues such as patient protection, renal stones, sexual health and well-being, urostoma management, male incontinence, pain management and antimicrobial resistance, as well as emerging issues in transgender nursing care and the urological care needs of refugees and migrants.

Taking off from our discussions during EAUN18 in Copenhagen, we will report on the views expressed and work undertaken regarding the development of a urological nursing education curriculum in Europe. We will also be asking the question – 'Where is urology nursing in our changing world?' as we seek ways to support each other and 'future-proof' our practice. Expect all these activities besides our regular offer of dedicated nursing poster sessions, special interest groups in both bladder cancer and continence, discussion of difficult cases, video sessions, ESU Courses and the Research Competition segment. We have hospital visits, the well-attended Guided Nurses Walk and Congress Dinner, among other activities.

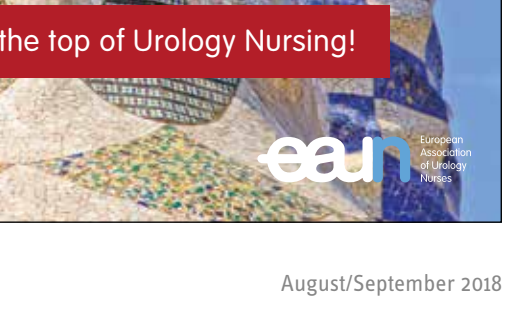
For the complete Scientific Programme visit www.eaun19.org

All in all, EAUN19 will be a very tasty urological nursing tapas and we want you to join us!

Share your clinical practice or research insights by submitting an abstract. Innovation, when shared, will build an ever stronger community of urology nursing professionals.

Save the date!

Details of EAUN19 can be found at www.eaun19.org. Check the link for information on the venue, the Scientific Programme and links for submitting abstracts. Abstract submission is now open, so don't delay! You can also find details on how to apply for the EAUN Travel Grant worth €500. Registration opens 1 October 2018 (the early fee deadline is 15 January, 2019).



Come and join us at EAUN19 Barcelona, it would not be the same without you!