The development of a supraregional network for the management of penile cancer

P Kumar¹, S Singh², JC Goddard³, TR Terry³, DJ Summerton³

¹Barts and The London NHS Trust, UK

²Sherwood Forest Hospitals NHS Foundation Trust, UK

³University Hospitals of Leicester NHS Trust, UK

ABSTRACT

INTRODUCTION Although its incidence is increasing, penile cancer remains a rare disease in the UK. In view of this low volume, the National Institute for Clinical Excellence recommended that treatment is centralised in a limited number of centres arranged as supraregional networks. The aim of this centralisation is to allow the best standardised treatment for the primary tumours and nodal disease, thereby avoiding under or overtreatment. In this paper we review the formation and functioning of our network in the East Midlands.

METHODS Data were collected up to August 2010 from our prospective penile network database since its inception in 2005. These data were analysed to see our workload, patterns of referral and surgeries performed over this time period.

RESULTS The structure and function of the East Midlands network are described. There has been an increase in the number of cases discussed since its formation. There has also been a trend towards more conservative surgery, both of the primary tumour and of nodal management. Between September 2009 and August 2010, 16 glansectomies were performed versus 5 total and 9 partial penectomies. The same period saw 18 dynamic sentinel lymph node biopsies against 7 bilateral and 3 unilateral superficial groin dissections. There was a very high patient satisfaction rate, with patients feeling they had good support and information.

CONCLUSIONS On reviewing the literature it can be clearly seen that supraregional networks have led to a decrease in overtreatment and better recognition of the need to manage lymph node status optimally. Our network has demonstrated the trend toward conservative surgery and sentinel node biopsy. The formation of supraregional networks with a multidisciplinary approach will facilitate high volume centres that will offer optimal surgical therapy and also allow recruitment into studies and new chemotherapeutic regimens. It will also allow better data collection to aid clinical studies that hopefully will also demonstrate better outcomes.

KEYWORDS

Penile cancer – Multidisciplinary team – Sentinel node biopsy

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CORRESPONDENCE TO

Duncan Summerton, Consultant Urological Surgeon, Leicester General Hospital, Gwendolen Road, Leicester LE5 4PW, UK
T: +44 (0)116 258 8260; E: duncan.summerton@uhl-tr.nhs.uk

There has been an increase in penile cancer over the last two decades in the UK from 1.1 cases in 100,000 men in 1985–1987 (272 cases per year) to 1.4 cases in 100,000 men in 2004–2006 (385 cases per year).¹ Penile cancer still remains a rare entity with the average urologist seeing one case per year.

It is essential to ensure that these patients receive the best treatment based on consensus and exposure to best evidence-based practice. The rarity of penile cancer led the National Institute for Clinical Excellence (NICE) to recommend: ‘*Specialised penis cancer multidisciplinary teams (MDTs) should be established jointly by two to four neighbouring networks. Each of these teams should serve a population base of four million or more and expect to manage a minimum of 25 new patients each year.*’²

Due to the low incidence of penile cancer, there is very little evidence-based literature on therapeutic outcomes. This favours the concept of specialised MDTs to oversee the management of the disease. There are areas of contention concerning management of both the primary tumour and even more so that of the inguinal lymph nodes. A number of groups have quite convincingly demonstrated that the wide margins of clearance for treatment of the primary tumour that were employed traditionally are no longer necessary.³ The role and extent of prophylactic lymph node dissection remains controversial.

Penile cancer is an emotive disease. Both under and overtreatment can have considerable short and longer term repercussions. It is established that conservative surgery is associated with an increased quality of life⁴ compared with

penile amputation.⁵ One of the main aims of supraregional networks is therefore to standardise treatment in order to minimise the risk of inappropriate management while maximising benefit and to allow the safer use of more conservative treatments wherever possible.

As the population of the UK is estimated to be about 60 million and taking into account certain geographical and population density issues, the British Association of Urological Surgeons (BAUS) envisaged the formation of 10 supraregional centres for penile cancer care. This paper examines the formation of such a supraregional network for penile cancer in the East Midlands. Its structure and function are described, and the advantages that this approach yields and how it might further improve the delivery of penile cancer care in the future are discussed. Patient data from the MDT meetings since the inception of the supraregional network in 2005 are presented to demonstrate the activity in penile cancer care that the MDT oversees.

Methods

The data were collected from the penile network database, which has been maintained prospectively since the formation of the network. These data were used to analyse the workload between 2005 and 2010, looking specifically at cases discussed, referral patterns and the types of surgery performed. A patient satisfaction survey for those having already been treated has previously been retrospectively audited.

Structure and function of the East Midlands network

The supraregional network for penile cancer in the East Midlands is designed on a 'hub and spoke' model with the coordinating specialist centre based in Leicester. The other centres in the region are: Chesterfield, Nottingham, Mansfield, Burton and Derby to the north; Boston and Lincoln to the east; Kettering and Northampton to the south; and Coventry, Warwick and Nuneaton to the west. This gives an estimated population to be served of approximately 4.9–6.5 million.

The clinical team in Leicester directly involved in the MDT comprises three urologists with a specialist interest in penile surgery, a panel of three uropathologists, a medical and clinical oncologist with an interest in penile cancer, a uroradiologist also with a specialist interest, a dermatologist and two specialist urology oncology nurses. A designated plastic surgeon and a palliative care consultant with a specific interest in penile cancer are also part of the MDT. In addition, the MDT is able to call on a psychiatrist with an interest in psychosexual problems as well as a dedicated psycho-oncological counsellor.

The administration of the MDT is facilitated by a penile MDT coordinator based in Leicester to whom the details of each case are faxed on a proforma held by all the cancer centres and units in the network (Fig 1). A response is generated within 48 hours to confirm that the case will be discussed at the next MDT meeting. If it is felt that delaying a decision on treatment of a patient until the next meeting would be disadvantageous, a management plan is agreed

Data Collection		08-2G-415	
The Penile MDT records the minimum dataset for each patient on the referral proforma below:			
East Midlands Penile Cancer MDT - Referral Proforma			
Patient Demographics			
Hosp No:		Referral Hospital:	
Surname:		Original Consultant:	
Forename:		Date Referred by GP:	
DOB:		Date Referred to Leicester MDT:	
		Date Reply Sent:	
Diagnostic Events			
Biopsy/Circumcision:			
Hospital:			
Date:			
Grade:			
Stage:			
Histology:			
MR/CT	Date	Stage (TNM)	
Definitive Surgery			
Operation:			
Date:			
Hospital:			
Grade:			
Stage (T):			
Sentinel Nodes:	Positive?:		
Left Inguinal Nodes:	Positive?:		
Right Inguinal Nodes:	Positive?:		
Pelvic Nodes:	Positive?:		
Other Treatments			
Date of Other Treatment	Other Treatment Type		
MDT Meeting - Outcome Notes			
Date discussed	Outcome		
Clinical Outcome			
Recurrence:			
Date:			
Date Last Seen:			
Date of Death:			
<small>MDT Co-ordinator - Dawn Cave, dawn.cave@uhl-tr.nhs.uk - Telephone: 0116 258 4735, Fax: 0116 258 4733 MDT Chair Mr D. Summerton, duncan.summerton@uhl-tr.nhs.uk - Telephone: 0116 258 8260 Contact Details - Tim Terry and Jonathan Goddard: Tel Tim Terry - 258 4450 - Jonathan Goddard - 258 4448 tim.terry@uhl-tr.nhs.uk, jonathan.goddard@uhl-tr.nhs.uk</small>			
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Figure 1 Fax referral proforma

and also communicated to the referring centre within 48 hours. This management plan is made by consultation between at least a urologist and an oncologist with differing amounts of consultation and input from other members of the MDT as necessary.

The supraregional penile MDT is held on a two-weekly basis and cases are discussed using a multi-site teleconferencing system. This allows all units to discuss management options and outcomes face-to-face and in real time. Following the meeting, an MDT report detailing the discussion and any recommendations for each patient is distributed to the referring centres. A typed outcome is emailed and a hard copy posted within 24 hours.

While developing the supraregional service, considerable emphasis has been placed on maximising the integration of the pathology service into the process. The accuracy of diagnoses is confirmed by central review of biopsy samples in Leicester. When surgery is carried out in Leicester, the operating surgeon and pathologist meet whenever frozen sections are taken. The use of pre-operative and intra-operative digital photography together with close collaboration with the uropathologists ensures that there is no ambiguity in the orientation of the specimens. Visitations by

the pathologists to the theatre have been introduced successfully.

Results

The inception of the supraregional network occurred in 2005 and it can be seen that the number of cases being discussed has increased through each of the successive years with a gradual upward trend. From 2005 the MDT was performed by teleconference with the activity as illustrated in Figure 2.

The rising trend of cases being discussed reflects the acceptance and success of the supraregional network. Indeed, before its advent, penile cancer was treated in the region at many sites and by many different surgeons, resulting in a low case load per surgeon per year. As an example, in

Leicester in the five years prior to the formation of the supraregional network only 38 procedures were performed on 36 patients, which is only seven cases a year.

The successful uptake of the MDT in the region has not been a passive but rather a very active process. This has been due to interaction between clinicians in the region. This has been facilitated by an annual penile meeting as well as highlighting work and research performed at the annual regional urology meeting. This can again be seen by the distribution of referrals from around the region as noted for the last year in which there were 56 new referrals (Fig 3).

In the 12 months between September 2009 and August 2010 a total of 81 surgical procedures were undertaken. It can be noted from Figure 4 that there has been a move towards conservative penile surgery as evidenced by the decrease in the number of penectomies and the increase in penile preserving procedures such as glansectomy. Simi-

Figure 2 Trend of cases discussed with multidisciplinary team

Figure 3 New referrals by centre over 12 months (September 2009 – August 2010)

Figure 4 Operative procedures performed over 12 months (September 2009 – August 2010)

Table 1 Patient satisfaction survey

Questions	Yes	No	Unsure	N/A
Were you offered the contact details of a key worker who would be your link at the hospital during your treatment?	67%	0%	20%	13%
Were you offered patient information leaflets about your cancer?	100%	0%	0%	0%
If you looked at the leaflets, were they easy to understand?	67%	13%	13%	7%
If you looked at the leaflets, were they helpful?	67%	13%	13%	7%
Do you have any suggestions for other information that you would have found helpful?	7%	67%	13%	13%
Were you satisfied with the involvement you had with planning your treatment and care?	100%	0%	0%	0%
Did you understand the explanations given to you about your treatment?	100%	0%	0%	0%
Did you get the chance and time to ask any questions about your treatment?	100%	0%	0%	0%
Were your family's worries or concerns discussed?	100%	0%	0%	0%
Did you feel you had respect and dignity throughout your treatment?	100%	0%	0%	0%

larly, it can be noted that the majority of lymph node work undertaken is dynamic sentinel lymph node biopsy (DSLNB).

We have audited our own outcomes, having carried out a patient satisfaction survey (Table 1). Twenty-five patients were sent questionnaires and fifteen responded. The survey noted that the majority of patients were satisfied, with all of them feeling that they and their families had had sufficient understanding and explanation of their treatments. An essential factor is the availability of a designated and dedicated key worker, which greatly aids the pathway of the penile cancer patient. We try to ensure this availability as we believe it improves overall understanding as well as satisfaction. Additionally, the written information was found to be useful and understood by the majority of the patients.

Discussion

Richie *et al* analysed the BAUS database with regards to the management of penile cancer over a decade ago.⁶ Their work provides an insight into penile cancer management before the era of the specialist MDT and supraregional networks. They noted that experience in managing penile cancer was spread thinly at the time of the study, with the maximum number of cases being five by one consultant and the most in any one centre being eight. There was also quite a variance in treatment with a tendency to over or under-treat. Thirty-nine per cent of patients with stage 1 disease were treated with partial penectomies while thirty-three per cent with stage 4 disease were managed by local excision only. Their findings confirm the need for standardisation and quality assurance, which the advent of supraregional networks will deliver and maintain. Although recently developed guidelines for penile cancer have been helpful,⁷ evidence from clinical trials is lacking.

A further aim of the supraregional MDTs is the discussion of difficult cases where the pathology or staging is uncertain. This is an aim that has been met in our experience where confirmation of pathology together with appropriate imaging gives confidence that appropriate management is taking place. Indeed, it is established from the literature that expert

central review of pathology and radiology improves decision making and adds quality control to the MDT process.⁸

In this series, we report the trend towards conservative surgery and avoidance of overtreatment. As a result of the absence of clinical trial data, the standards of care for aspects of penile cancer, in particular the management of regional lymph nodes and adjuvant therapy, are lacking. A supraregional approach allows discussion of therapeutic options in such instances and, hopefully, will lead to locally agreed methods and the establishment of standard therapy. While the surgery of the primary lesion is less contentious, the failure of adequate assessment and therapeutic management of lymph nodes will result in treatment failure.

A supraregional network may be defined as a group of individuals with a specialist interest or expertise in a disease where the host trust is likely to have access to specialist treatment facilities. This is the case in our network where the designated clinician from each centre is involved in the management of all the cases from that centre. Patients are treated at their local centres where appropriate within the guidelines and follow-up appointment are offered locally or centrally, depending on patient preference. Although not all patients are seen or their histology necessarily reviewed at the coordinating centre, this facility is available for any case in the region.

In this paper the development, structure and function of our supraregional network for penile cancer has been detailed. While data showing the clinical throughput of the network have been presented, the clinical data are not sufficiently mature for comments to be made about outcomes and possible changes in practice. Naturally, it is our feeling that greater organisation, collaboration and scrutiny of patient management for penile cancer will lead to improved clinical outcomes.

Two centres in the UK have recently presented comprehensive clinical data for their series of penile cancer patients, one in the form of a retrospective audit⁹ and one a prospective study.¹⁰ The data from the retrospective audit are derived from patients treated between 1993 and 2003 in a cancer network that overlaps ours geographically. It is

interesting to note how data from our network reflect the change in management of the primary tumour that has occurred since the patients studied by Mistry *et al*⁹ were treated. Eighteen of the sixty-five patients diagnosed with penile cancer in their audit were treated primarily with radiotherapy. Eight of these patients suffered disease recurrence and went on to have a partial or total salvage penectomy. Among the 42 patients treated surgically for their primary tumour, only 3 underwent a glansectomy.

Radiotherapy as primary treatment among our patients is a rare event with only 2 of the 153 patients discussed being treated in this way. Glansectomies were employed in 22 patients with a partial glansectomy in 3. This change in management reflects the trend to try and cure patients with the minimum of functional or cosmetic compromise. The traditional view was that a 2cm margin of resection was required to achieve oncological control but Minhas *et al* demonstrated that good control can be achieved with margins of only a few millimetres.³ Many of the tumours that were previously managed by partial penectomy can therefore now be treated by a glansectomy or a conservative partial penectomy (which we have referred to as a distal penectomy) with reconstruction where appropriate.

Although it is accepted that patients who suffer disease recurrence after radical radiotherapy often do well with salvage surgery, the functional and cosmetic results after radiotherapy are often unreliable and clinical surveillance following radiotherapy is more difficult. Moreover, patients who develop local recurrence after conservative surgery can equally be managed by partial or total penectomies. For these reasons, radical radiotherapy as a treatment for penile cancer is becoming less popular and this trend is seen among our patients.

It is also interesting to compare the activity of our supraregional network with that reported by Mistry *et al*.⁹ They present data for patients with penile cancer from a population of around one million. Over a 10-year period, 65 patients were diagnosed with penile cancer. As the catchment for our network is approximately six million, it is to be expected that the throughput of patients is much larger. Over 50 new cases per year are now being discussed at our supraregional MDT, which should convey all the benefits of this approach as outlined above. The supraregional MDT concept is further validated by the fact noted earlier that prior to 2005 approximately seven cases of penile cancer were operated on at Leicester per year.

Conclusions

We have outlined the establishment of a supraregional network for the management of penile cancer in the East Midlands. This service has been developed in response to guidance from NICE on how this rare cancer should be managed in the UK. It has been demonstrated that by centralising penile cancer management in this way, both patients and their carers benefit. Our survey of patients also notes that most patients are indeed satisfied with their treatment.

The workload of penile cancer surgery in the coordinating centre has increased ten-fold and continues to increase.

We now aim to offer all suitable patients in the region DSLNB where appropriate. This is evidenced from our figures for September 2009 to August 2010 with 18 DSLNBs compared with 10 superficial dissections. We envisage the number of DSLNBs to increase with each year. It is clear that the supraregional network has already led to an increase in the rate of conservative management for early penile cancer. We further hope to contribute to the national data that are accruing from other supraregional centres with regard to the management of patients at high risk of lymph node disease so that the optimum management in such cases can be defined more clearly.

The size and organisation of the East Midlands supraregional network with a dedicated penile cancer oncological service has also helped with the recruitment of patients into clinical trials. The region was the first to recruit for a phase II trial of docetaxel, cisplatin and 5-fluorouracil chemotherapy in locally advanced and metastatic carcinoma of the penis. A centralised referral system to Leicester therefore allows coordination and screening of patients for recruitment to trials.

The penile network can be modelled as a systems modelling exercise⁸ and can be thought of as a process akin to operations management. The output is very much dependent on the inputs and the quality of processing in the system. We have been fortunate in having good inputs: referral information and enthusiasm from satellite centres together with good processing by dedicated committed specialists in a robust MDT framework. The MDT peer review process has provided valuable feedback for achieving the best out of the system and for optimising it on a dynamic basis by further improvements. The importance of patient education, information and support has been crucial to the successful running of the network and we have aimed to provide good written information and adequate support including oncology nurse as well as psychological support with a psycho-oncological counsellor.

As noted above, the trends in penile cancer have shown an increase in incidence over the last 20 years but there has been no significant change in age-standardised mortality rates or overall five-year survival.¹ Hopefully, with the centralisation of penile cancer services, we will see an improvement in the quantity, quality and completeness of data collected, which will allow us to answer some important questions. It may reveal why we are seeing an increasing incidence in penile cancer by analysing the various socio-demographic factors. It will also allow us to audit the actual outcomes better and establish whether the formation of penile networks allows us to significantly affect outcomes including survival. The East Midlands network is the third largest in the country and this has facilitated collaborative work such as the development of DSLNB, recruitment into clinical trials and clinical research.

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Correspondence

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